N S T I T U T E

Dementia and I

Marko van Gerven MD Christina van Tellingen MD (Eds.)



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BOLK'S COMPANIONS

About the Kingfisher Companion Group

The Kingfisher Companion Group aspires to broaden the perspective of science by elucidating the context behind health and disease. To this aim, the Group strives to pioneer investigative methods to complement and innovate conventional scientific views and research techniques. It examines the exploration of conscious-intuitive study in the research and practice of medicine such as the 4-step approach employed in the Bolk's Companion series. The Kingfisher Foundation supports this development of new approaches for medical practice both logistically and financially.

The Kingfisher Companion Group works at the Louis Bolk Institute where scientific research to further the development of sustainable agriculture, nutrition, and healthcare has been conducted since 1976. The basic tenet of the Institute regarding the life sciences is that nature is the source of knowledge about life. Through its groundbreaking research, the institute seeks to contribute to a healthy future for people, animals, and the environment.

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Louis Bolk (1866-1930) was a professor of anatomy and embryology at the University of Amsterdam. He developed and employed comparative scientific methods of investigation that conveyed new insights into his subjects. With the insights he gained, he was able to place his subjects into a meaningful context. To employ his method, he instructed his students to use the 'macroscope' rather than the microscope! Dementia and I Marko van Gerven MD Christina van Tellingen MD (Eds.)

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BOLK'S COMPANIONS ON THE PRACTICE OF MEDICINE

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About the Project

The project Renewal of Medical Education, aims to produce Companions that complement medical study by demonstrating how the insights of current biomedical science can be broadened by the insights of inclusive thinking inherent in comparative science. Companion authors apply a scientific methodology that uses four consecutive steps to achieve an integrated understanding of wellness and disease. These steps are described in Chapter 12 as the *4-step* approach. This approach seeks to recapture a coherent and comprehensive understanding of human nature and the environment. BOLK 'S COMPANIONS FOR THE STUDY OF MEDICINE are designed to complement medical education, specifically as it relates to human facets of current biomedical sciences.

BOLK'S COMPANIONS FOR THE PRACTICE OF MEDICINE contribute to a broader scientific basis for the clinical years of medical study and for developing the intuitive facets of medical practice.

BOLK'S COMPANIONS ON THE FUNDAMENTALS OF MEDICINE explore fundamental medical concepts and seek to broaden the medical paradigm.

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Thank you all! Marko van Gerven MD Christina van Tellingen MD

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1.Introductionby Christina van Tellingen MD

Dementia or neurocognitive disorder (DSM-5) is, in many ways, a complex syndrome: for the patients and their close relatives the disease poses a frightening reality of loss of cognitive abilities, drastic changes in behavior, and a new and sudden dependence on others. For the physician who must diagnose and prepare family members for the steady and progressive nature of the illness, dementia can pose a taxing treatment process, as there exist no effective therapeutic options. For therapists and caregivers who provide emotional and logistical support to patients and families, dementia challenges the pursuit of creative treatment modalities and communication techniques to ensure adequate and purposeful contact with the demented person. To add to the complex nature of living with and treating this disease, the most common form of dementia, Alzheimer's, has no clear diagnosis, cause, treatment, or outcome, according to the neuroscientist professor Peter Whitehouse and others (Whitehouse 2008; Maassen 2014; see also Olde Rickert et al 2012, Chapter 8).

The following case history illustrates how difficult it is to diagnose Alzheimer's disease as a distinct disease entity, and recounts the patient's profound personality changes as well as his family's many challenges in daily life.

Mr. A is 76 years old at the first visit. He complains that his memory has slowly deteriorated over the past six months. He cannot recall whether he accomplished his tasks of a few days ago or even of a few hours ago or not. His youth and events of the more distant past he remembers very well, however. To his great relief, he also remembers how to play the piano pieces he likes and enjoys so much. His wife had previously noted that there were problems: In a reading group he cannot adequately answer the questions that were previously easy for him, and it seems to her that he is less clear in his thinking.

Mr. A relates that he has suffered from moderate hypertension (175/90 on average) for forty years. High blood pressure is common in his family, however, he has never

opted to take medication. A recent ECG was normal. He has a problem sleeping, often waking up at 3 AM and subsequently has trouble falling back to sleep. When speaking about important events in his life, he relays a difficult childhood and that he was in hiding for a number of years during World War II; his two previous marriages ended in divorce. There is no history of dementia in his family.

On physical examination, he has a blood pressure of 190/95, examination of heart and lungs is normal. He does have an arcus senilis¹. He remembers his own name, that of his wife, and the name of the physician. He does not know exactly what date it is, or the day of the week. He knows where he is.

On the basis of this information, a mild neurocognitive disorder can be suspected, possibly on the basis of high blood pressure or incipient Alzheimer's dementia. Mild (natural) sleep medication is advised next to anti-hypertensive treatment. The patient refuses blood pressure medication since he has been well without it for forty years and so have his relatives, even after he is advised about possible negative consequences. It is recommended that he be active physically by walking and playing the piano regularly and to train his memory by reversing words, saying five or six lettered words backwards every day. In the following six months, his condition does not markedly deteriorate and his blood pressure exhibits improvement (150/80). His memory fluctuates but does not worsen.

In the seventh month after the first visit, Mr. A checks in for an emergency visit with bumps on the temples, pain on top of his head, and sudden double vision. His face looks somewhat swollen; the temples are painful on palpation with bilateral pulsating small bumps arranged in strands. His temperature is 37.5° C and his blood pressure 185/85. The internist confirms the diagnosis of temporal arteritis. His ESR² is increased to 50 mm/hr (normal range 1-10). Cholesterol has remained normal at 4.4 mmol/L (3.9-6.5), as has the glucose at 5.9 mmol/L (3.3-6.0). He is started on 40 mg of prednisolone, and an ACE inhibitor for his hypertension, which he promises to take. Some days later, he reports that the headache has improved and the bumps are gone, but his memory has declined considerably. He can no longer keep up with the days of the week, feels disoriented, and suffers from mood swings and anxiety. His blood pressure is 145/80. The ESR has returned to normal and a tapering regimen for

¹ a lighter colored arc on the periphery of the iris that may appear at a later age

² sedimentation rate of the blood

prednisolone is initiated.

Three weeks later at an emergency home visit, Mr. A is apathetic, does not move or speak, and cries when he finds that he cannot lift his arms on request. During the previous two days, he has often seemed absent. He now takes 22.5 mg prednisolone. After a normal CT scan of the head the diagnosis catatonic delirium, likely secondary to prednisolone reduction, is established and he is admitted to the local hospital and started on 1 mg/day of haloperidol. There, the prednisolone is rapidly reduced and his catatonia improves. A week later, however, haloperidol must be ceased because Mr. A develops extrapyramidal symptoms.

The reaction to haloperidol is described inter alia in Lewy body dementia. This possible diagnosis is in addition to the two other possible forms of dementia Mr. A could have: vascular dementia and/or Alzheimer's disease.

Once home, Mr. A returns to his normal self, but his memory functions deteriorate considerably. The following year, he suffers from two TIAs³, which leave him emotionally labile and less bright. This again, confirms a diagnosis of vascular dementia.

Mr. A's wife takes care of him at home in the time following, but after several years of further deterioration, sometimes gradually, sometimes in jumps that are likely due to renewed small strokes, he experiences increased difficulty performing his ADL⁴ and it becomes harder to emotionally uphold himself. As his memory worsens, he is admitted to a nursing home. At that time, he still recognizes his wife and brother and regularly plays the familiar music on the piano. During his wife's frequent visits, they speak a lot about the past. This deepens their relationship and makes it possible for him to face some of the difficult moments in his life, including childhood experiences, memories from World War II, and his divorce circumstances. It eventually allows him to give these events a place in his life. At times, he is pessimistic about the loss of his mental capacity and physically, he gradually deteriorates. Despite regular physiotherapy, movement therapy, music therapy, and art therapy in the nursing home, he eventually can no longer walk or talk. His humor and the piano playing help him through the difficult periods. He dies in a peaceful mood almost eight years after the first visit when the diagnosis of mild neurocognitive disorder became apparent.

³ transient ischemic attack, a temporary loss of brain function due to a reduced blood supply

⁴ Activities of Daily Living

The story of Mr. A illustrates how complicated it is to diagnose a specific type of dementia. Initially, he would seem to only experience memory problems, in keeping with Alzheimer's Dementia. After the prednisolone induced delirious state, symptoms of vascular dementia become more apparent. In the later stages, it becomes increasingly difficult to assign the existing symptoms to a specific dementia. The incremental deterioration with sudden jumps, the emotions and mood swings are also more consistent with a vascular dementia.

Despite the uncertainty surrounding the diagnosis, the various interventions during the dementia process have a favorable effect on Mr. A. His wife is helpful in the processing of emotions. The various therapies as well as playing the piano have a supporting role. Some of these interventions are based on ideas that arise from medical/therapeutic intuitions acquired in practice. This Companion is written to more closely examine the gap between knowledge about dementia (which is rather deficient) and effective daily practice in the support of people with dementia. Bridging this gap seems possible when we remain aware that the person with dementia can still be 'reached' and remains open to communication given a supportive and conducive therapeutic environment

This Companion consists of three parts.

Part I (Chapter 2-6) describes effective daily practice in the treatment of elderly people with dementia.

In Part II (Chapter 7-12), discusses the diagnostic criteria and known risk factors of dementia. Part III (Chapter 13-16) expounds on a number of specific issues related to the dementia process. Part I Experiential and Practical Research

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Introduction to Chapters 2-6

Therapists and care givers appear to not use the DSM classification in daily practice, but rather *four stages of shifting I-experience*. For them, knowledge of the diagnosis plays a smaller role than the course of dementia over time.

The Dutch psychologist *Rien Verdult* (Verdult 2003) developed a scheme with four stages of changing I-experience in demented patients that correspond to publications in the United States by Naomi Feil, summarized in her book, The Validation Breakthrough (Feil, 2010). The term 'stages of shifting I-experience' refers to the fact that varying forms of communication are required depending on the course of dementia and not on a list of symptoms.

Verdult distinguishes:

1. Stage 1: the **'endangered'** I. "The demented person tends to hide the early signs of their uncertain future, trying to obfuscate their own doubts and insecurities about the impending disease. There is an accumulation of experience of loss, physical, personal and social". Feil calls this the **cognitive** phase;

2. Stage 2: the **'stray'** I. "Autonomy and identity loss take larger forms, and an increasing fear becomes more palpable. Panic and desperation are commonplace. The loss of autonomy is driven by loss of control and an increasing distancing from the individual's reality, routine, and environment. The demented person is increasingly confronted with unconscious aspects of his past. Essential aspects of the personality change. They get 'lost' in their own lives. As past and present increasingly become intertwined, it is difficult to form an adequate picture of themselves and of their own situation." Feil coins this the **emotional** phase.

3. Stage 3: the **'hidden'** I. "With the progression of dementia, the older person pulls further back into their inner world. They are seemingly lost in thought, or walking aimlessly, shuffling around. They often exhibit repeated movements, sometimes in response to a stimulus or a need for contact, sometimes due to overstimulation/excess sensory stimuli. Because the behavior is seemingly incomprehensible, the environment conforms to isolate the demented person." Feil calls this the **motor** phase.

4. Stage 4: the 'receded' I. "In the last stage of the dementia process demented people become

increasingly isolated. Demented people seem to increasingly live in their own world and that world is progressively less part of a 'shared' world... it is a form of isolation, which cuts off the demented person from both themselves and from the environment. The perception of time, space, and of one's own body is probably lost. Self-awareness has become very limited or is lost." For Feil this is the **sensory** phase.

Describing the successive stages of I-perception is helpful in lending practical tools to assist people with progressive dementia. These are expounded upon in Chapters 2-6.

Experience shows that positive encounters with demented people may continue until the end of life, even though the body and conceptualization of the 'I' seemingly fall away. Several examples of this will be given in the following chapters. This experience seems to indicate that people resemble instrument players: the 'I' itself lives on but the appearance of the 'I' is greatly altered.

Preview of Part I

In Chapter 2, *Artistic Reminiscence*, art therapist **Jacqueline Stoo**p describes how she appeals to the healthy side of the I-experience. This method applies particularly to the first stage of Verdult, the 'endangered' I-experience.

In Chapter 3, *Crafting Context*, in which a creative encounter with the other(s) is staged, **Marjolein Baars** accompanies the elderly and describes how to focus on people with different stages of dementia with personal, narrative, and musical 'instruments', both in groups and individually. This contribution concentrates on the second and third stage of loss of I-perception, the 'stray' and the 'hidden' I.

In Chapter 4, *Finding Self in Image*, art therapist **Mieke Merckx** describes how she shapes communication in the third and fourth stages of shifting I-experience.

Chapter 5, *Where Words Fail, Music can Speak,* by music therapist **Connie Alblas** shows, a format for working with music based on the fourth stage of I-experience.

Chapter 6, *End of Life Care and Dementia*, by geriatric physician **Marie-José Gijsberts**, deliberates on the approach to dementia on the basis of the four Verdult stages and discusses judicial mental competence, palliative care, and spiritual aspects of dealing with the end of life.

Artistic Reminiscence: The Fruits of Life by Jacqueline Stoop

Sunday Morning

The light begins to wander in our home and touches things.

We eat our early bread dipped in sun.

You spread the white tablecloth grasses arranged in a glass. This is the day that work rests still. The hand palm open to the light.

Ida Gerhardt (1971)

2.1. First Example of Slow Narratives in Swift Time: 'Your Own Hands'

Mr. B comes in, while Mrs. C and Mrs. D are already seated at the large table. Mr. B greets the two ladies and the art therapist. The morning unrolls a stream of sunlight on floor and wall of the creative activities area of the part-time psycho-geriatric ward. There are flowers on the table and large prints of art: studies of hands by Leonardo Da Vinci and Michelangelo; drawings by Vincent Van Gogh, with hardworking peasants sowing, binding sheaves; an impressionistic painting from the Hague School: fishermen mending their nets; a sculpture of clasped hands by Auguste Rodin. There is also a folder with narrative on the table. The theme of this second meeting of the Fruits of Life project is 'your own hands.'

The art therapist reads a short story from her narrative folder. It is called 'Counting your blessings' and is about a woman who relates to her doctor all the grief that

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has happened to her, counting it on the fingers of one hand and on the fingers of the other hand counts her blessings. "When she folds her hands together, then the blessings cover the grief and she can still live her life," she says to her doctor. Mr. B and the ladies C and D have listened attentively and sometimes shown recognition by nodding their heads. Mr. B has folded his hands and Mrs. C is studying her hands and their large and small joints. Mrs. D listens quietly and introvertedly. She seems to be both present and simultaneously withdrawn. Along with the art therapist, the participants view the art prints and contemplate on the shape of the hands. What hands are young and which hands lived-through, what hands are tired and which radiate power. How can one see whether or not folded hands are folded in prayer. The conversation covers all these aspects.

Mr. B says that he comes from a family of fishermen and as a little boy helped repair the nets. But he himself went to work in an office and that you can see from his hands, he says. They are not workman's hands, but desk hands. The art therapist invites all three participants to lay their hands on the table and to observe them well. She also does it herself. They look at each other's hands with care and attention and name what the hands tell them. Not all hands can be laid flat on the table. They sometimes make quirky odd angles due to their tired or aching joints.

Then everyone is asked to tell about fond memories related to their hands. What were their hands good at? What did they do, carry, care for? Did they comfort, cradle, earn the daily bread, make new things, did they sow, harvest? With emotion, dignity, and enthusiasm they tell each other and themselves stories in slow motion, about their hands and about important moments in their lives. The introspective Mrs. D explains that she was still very young when her mother took her to her grandmother's, where she was raised. That she was always making things with her hands, how they drew and painted, and colored in forms that emerged in all tints. She speaks softly, and her voice becomes even softer when the emotion arises with a single tear as she relates that she is happier with the upbringing by her grandmother than by her mother's. Mrs. C recounts how she subtly directed her horses with the reins. Her hands could do that with slight movements, without brute force and her horses knew all the signs her hands gave them. She keeps repeating and repeating, and her body and her hands again encourage her horses and her gaze focuses on a distant goal. Mr. B waits quietly for the moment when he can tell a treasured memory about his own hands, visibly pleased with the art therapist's question. Until that time he listens attentively to the stories of his peers. The most precious thing he ever carried in his hands is his daughter immediately after her birth, he says. Meanwhile, he brings his two hands together and folds them into a cradle. He carried brand new life, she was immediately laid in his hands .. his expression is as if it had happened yesterday. His daughter still lifts him above all sense of time and space. For a moment, there is a shared intimate silence, from these precious memories of their own hands.

Then the participants each receive a large piece of drawing paper. They lay their hands on it and the art therapist draws the contours of each pair of hands on the paper with a pencil. Large boxes of pastel chalks in rich color pigments are put on the table. She invites the participants to choose colors that do justice to the precious memories of their hands and color in the space around their hands and the hands themselves with the pastels. She briefly shows how you can work with them, how the colors can be mixed with the fingers and how light areas can be saved. After the earlier exchange in the more communal portion of the exercise, Mr. B and the ladies *C* and *D* now work long and diligently in their own color world. They mix and expand the colors across their palate and then further combine the colors, play with colors or select a spectral color area for a part of the composition. The therapy room fills with calm deep breaths and the murmur of soft pastel chalk on the canvas. The rich silence that emerges creates space to work in. When everyone gradually reenters the here and now, some still playing with a piece of chalk, the therapist invites them to write out the precious memory with one word in the palms of the drawn hands. If they find that difficult, she assists.

Proudly and graciously, they show each other their artistic effort, highlight color choices, and appear more than happy with their work. Mr. B has mainly kept to various shades of pink, because he still lives in a kind of pink cloud through the birth of his daughter, he says. In his large old-fashioned handwriting, he inscribed 'my

daughter' in the palm of his hand. The participants wash their hands and the art therapist attends to each pair of hands with some rose cream. No one really wants to leave. All artwork is put away safely in each one's own golden Fruits of Life folder.

2.2. Second Example of Slow Narratives in Swift Time: 'Your Own Feet'

Mr. E would like to be interviewed for a documentary made by the institution. He has participated in another group of the course Fruits of Life and the golden Fruits of Life folder, an important treasure of his experiences and insights, lies next to him. He articulates his hope that the documentary make it possible for more elderly to enjoy Fruits of Life. Mr. E had to face brain injury after suffering a stroke with a brief coma. It led to physical limitations, damage to his short-term memory, and mood problems. With great determination, he completed physiotherapy to improve the physical damage left by the stroke, but he still felt that he could not recover a part of himself. Sadness and helplessness overtook him. With a strong German accent, he relays what participation in the program has meant for him, speaking with joy and emotion in his voice. There are flowers on the table and sunlight plays in the creative activities area. He asks the art therapist to show the landscape painting he has made with hills and large expanses in loose green and yellow tones in relation to the third theme: 'Where your feet brought you.'

On his small feet, in 1945, he is only nine years old. He walks with his mother, driven away from Sudetenland (an area in the northwestern part of the Czech Republic) taking flight to a devastated Germany. Day after day they walked together, hand in hand, fleeing through fertile landscapes and small villages. He heard the birds sing and smelled the fields, and he felt his mother's strength and courage as she walked with him to another life. The flight itself, of course, he never forgot. However, the question where his feet had brought him led him back to the walking, the colors of the landscape, to the road where he had heard the birds singing in unspoken anticipation of life, hand in hand with his mother. This enabled him to regain direction for himself and his tired feet following his debilitating stroke, and he saw how he could continue his life's path after his illness. His eyes shine as he looks longingly at his cherished landscape painting.

2.3. Inspiration and Subsequent Development of The Fruits of Life

Even when one thinks of the past one goes ahead, and so I would say that relived past is always future.

Mr. Bommel (Toonder 1953)

The course Fruits of Life is an 'artistic reminiscence' project. In the first phase of dementia, the phase of the 'endangered' I, artistic reminiscence projects use the memories of people as a therapeutic device (see also 2.4.). The Fruits of Life seeks to connect a strong desire in older people to look back on important life events, narrate about, and share them with others. The desire to remember past events becomes more explicit in exceptional life situations, such as when people hear they have dementia, and the borders of familiar routine and its meaning stave in, anticipating eventual admission to a nursing home. Many elderly directly or indirectly question life and death, identity, belonging, values, and loss about who they were or can continue to be. These questions provide the basis for reminiscing about life and open a doorway for individuals to process past experiences and give meaning, purpose, and agency to the aging person.

Loneliness lurks in periods of transition when the older person is frequently alone, especially in early onset of dementia when the gradual loss of short and long term memory is perceived as a major threat. Biographical memory is an important foundation of the acquired I-experience. It offers possibilities for insight and context-experience that can reveal the awareness of a deeper destiny.

Most elderly experience the natural need to look back and experience meaningfulness in such transitions. For them, we created the Fruits of Life. Also people who can still function at home benefit from artistic reminiscence projects. They implicitly or explicitly perceive their existence as especially vulnerable because they live in a cognitive twilight area between their past life and the looming timeless and indefinite life segment ahead of them. Who will they become and who will

they always continue to be? How and by whom may they still be known and met? Who can remain close to them when their life's paths have become unknown to themselves? The need to connect to and deepen prominent life moments while in that time of transition is associated with a profound yearning for meaning and for finding peace with their own situation.

A partnership of inspired art therapists examined how artistic means might provide opportunities to the elderly for contact and getting together in disarming, welcoming, and dedicated care settings that can nourish body, soul, and spirit.

2.3.1. Exploration of Artistic Therapeutic Experience in the Elderly

As the need for further education and deepening of the work with older people with dementia emerged, a collaboration was initiated between artistic therapists in regular and anthroposophic nursing homes for the elderly. The shared experience and practical case studies from psycho-geriatric wards revealed that despite physical deterioration, cognitive disorientation, and emotional confusion, the human mind can unexpectedly remain crisp, requiring individual artistic encounter and subtle tuning. Through this collaboration, we came to the understanding that besides individual artistic therapy and support, there also needs to be a more focused group therapy. This therapy form can offer an artistic program that is life-stage specific, in which small groups of older people work together. The shared inspiration, commitment, and empathy led to the intuition to expand on the theme of harvesting in an artistic manner, gathering the fruits. The Fruits of Life announced itself.

2.4. The Fruits of Life and Artistic Reminiscence

Reminiscence art work is an art form for elderly people with early dementia. It offers an artistic program in which dear memories are central. Reminiscence art is an intervention that does not explicitly give the unprocessed events of life a central place; rather it brings the intimate, vital, and dear and precious moments of life to mind. These moments have played a major role in the establishment and realization of individuality and identity.

The functional approach of the course Fruits of Life illumines the importance of the dear and precious in the life story. It highlights a more sustainable domain than the exact chronology or an interpretation of the events of life. It delivers powerful images of the Self in which important experiences and moments have merged. These images of durable memories and experience remain accessible to the elderly in the domain of emotions such as tenderness and joy.

2.4.1. Dear is What is Enduring

'Dear' is different from beautiful, fine, or nostalgic. Etymological dictionaries describe dear as belonging to the domain of attachment and affection. The word is associated with precious, near and nearby, and of great value. Dear life events refer to a more transcendent domain where light and shadow play together—the moments that might have invited us to be or have the courage to become who we are. People are very attached to those formative moments of life. Dear is also what is enduring. In early dementia, the threatening feelings of impending memory loss and associated mourning are feelings antithetical to those of peak life moments.

The Fruits of Life pursues a supportive, individual and collectively shared journey to these living pictures of the Self and provides artistic images of these identity-moments. Sharing the images of one's Self in a small group provides both the experience of being recognized and the feeling of connectedness. At the same time, people become aware of their uniqueness and how this relates to others.

2.4.2. Enduring Images; from Figurative Depictions to Color Mood

Art therapists are trained to gradually work from colorful moods filled with ambience to form, depiction, outline, and composition. In contrast, exchange in the art therapist-consortium showed that elderly people naturally prefer to work the other way round: from figurative depiction to colorful mood. We connected this phase in life with its gesture of letting go to an artistic perspective in which the real, earthly, and perceptible imagery of completed realistic paintings is exchanged for one with an ambience-filled color mood world with no clear shapes, as in the first example (2.1.). Elderly people are not only strongly formed in their physical appearance, they are also fully fashioned by their past in terms of soul and I-experience. It seemed rather logical and sensible to

adhere to that in the Fruits of Life. At the same time, members of the consortium were aware that artistic design skills of the current generation of elderly may not be consummate with the task of depiction and illustration.

The consortium conceived of the idea to provide rich and accessible artistic images at the start of a session that nourish, mirror, invite, and inspire clients to realize their own artistic efforts. The easy and straightforward painting techniques, the direct, or rather skimming lines of impressionist and expressionist art seemed appropriate for this objective. The aim was not to produce photographic reproductions of memory pictures, but rather to create an atmosphere-filled picture in which the elderly can experience the dear memories artistically. People's spirit could then be invited by the power of metaphor inherent in short stories or poetry to address and awaken precious memories and stimulate the imagination.

2.5. The Fruits of Life Program

The playful discovery of the layered geology of memories and important moments in life begins with a thematic group conversation that shares memories of a bygone era. This is followed by finding and sharing more personal, precious memories. In the end, the precious memory pictures are expressed artistically.

The sessions have a recurring structure to provide familiarity and safety.

a. The Thematic Group Conversation

The thematic group conversation begins with *harvesting from the clients' contemporaries*. The theme is introduced by means of objects, sounds, reading of small poems, music, art, graphics, etc. Common memories are awakened and shared of a joint history or time juncture through the conversation and/or of a specific cultural custom. Recognizable and familiar memories strengthen feelings of connection and community.

Then comes *harvesting and sharing one's own memories*. Addressing themes, searching and inviting one's own memories, recounting them, and listening to each other's memories supports the group conversation.

b. Ascertaining the Individual Connection to the Theme

The next focus is to *discover the individual and precious associations* with the theme and harvesting these for group conversation. This is linked with the images of the reminiscences in the treasury of the highly personal, autobiographical memory of each participant. Of course, the older person is left to decide for themselves what precious memories are important at that moment.

Then there is a break with coffee and tea.

c. Processing of the Memories, Narratives, and Experiences to Artistic Imagery

In the third phase of the process, the central task is to *represent* the ascertained precious memory pictures *artistically*. User-friendly artistic techniques and materials are utilized, supported by inspiring, simple art graphics, colorful ambience photography, or the appealing images of a poem (guided *expression*) to kindle the imagination.

Looking at each other's artistic work of fond transformed memory pictures places them in the center of consciousness in a colorful way and strengthens, interprets, and aids internalizing them (*impression*).

The Fruits of Life has proved to be an effective tool when working with older people, especially in the early stages of dementia, the phase of the 'endangered' I.

3. Crafting Context in Creative Encounter by Marjolein Baars

3.1. Case History

I walk into a living room of a small group in a nursing home. There is a quiet, somewhat lifeless atmosphere. I perceive introversion and islands. Each person present is in their own world—many different realities sitting at the same table. Around the table sit four people at different stages of dementia: a woman in a wheelchair, a gentleman in blue with a smile, a wakeful lady ("I will not do anything, I can do no more, I want nothing, and I enjoy doing nothing") and an elegant lady. One gentleman, whom I can hardly understand or reach, lies in a bed at the wall.

I introduce myself to those in the room one by one. I have a suitcase and a letter with me. I start to recount.

"I received a letter from my great aunt who has been on a journey." I pull out the letter and read it. "Dear Marjory, fancy what happened to me. I met a man who planted trees..." We slowly glide into the story. From the envelope I get an oak leaf and acorns, and pass them around. The attention grows. Everyone is now captivated and listens carefully. I observe that the atmosphere is slowly changing. The inward movement and individual island worlds are broken up. Each person moves in their own way to the focus point and the space created by the story telling. This generates an atmosphere which I would describe as light yellow and sparkling. Tender. Everyone present enters the story space at their own pace, level, and in their own manner. We come together in a shared space and time; we all are more awake, more alive.

Whether everyone understands what I'm saying or the meaning of the objects, I do not know. What I do know is that the story facilitates contact and connection between humans that was previously absent.

Out of the suitcase emerge more acorns and other seeds, and then, moments later, a small oak tree in a pot and eventually a bag with earth and pots in which to plant

acorns, just like in the story. The lady in the wheelchair is fascinated by the different forms and starts touching everything in a careful way. The gentleman by the wall that I can hardly understand and reach is present and follows what happens. His eyes are awake and though his gaze seems to come here from another universe, he certainly is present. I notice how he relaxes in the newly created attentive and lively atmosphere. Whenever applicable, I start a song 'Singing in the Rain', or 'Oh My Darlin' Clementine.' The wakeful lady sings along robustly, the gentleman with a smile in blue does too, in a jerky, jabbering way; the elegant lady hums and radiates. Each sings along in their own way. We take the time to make music and to listen. Then I pick up the thread of the story. When I ask them to do so, everyone smells the earth, but planting an acorn is asking too much. In closing, I get out some marzipan acorns. We nibble at these with a nice cup of tea that Sandra brings us. Everyone is satisfied. There is a lively atmosphere that feels rich. I put all props back in the suitcase and close it. One by one I say goodbye to them. I leave the seeds with the lady in the wheelchair. At my request as to whether she would take care of a small oak tree, the awake lady calls out: "No, really, I want nothing." So I take the pots with oak trees back home. We have all enjoyed our time.

3.2. Encounters

In the above event, *facilitation of a context for the encounter with others* is central. Since these others are in various stages of dementia and I am the initiator of the event, it is on me to create a context in which everyone can tune in their own way. This facilitates the person-to-person meeting, which brings me the following questions:

- What is my goal, which role (s) do I play and what are my premises?
- How do I prepare for it?
- How do I orient myself in the event?
- How do I tune in?
- What do I use to tune in?
- How do I know whether what I am doing is correct or useful?
- How do I act within the context in which we meet?

Now, eight years after the above event, I can articulate better what living and working with people with dementia is about. I can describe what I have experienced, researched, and practiced, and I can communicate these experiences to caregivers, volunteers, family members, and fellow artists. All participants present in the moment co-determine the direction of working in an event.

3.3. What is the Goal and Role(s) of the Coach, and What Are the Premises for This Work?

The goal is to create an event in collaboration with the other people.

The central role of the coach is initiating/facilitating the event. I choose the trigger for the event (a letter from my great-aunt). I take care of the props (acorns, leaves, etc.) and keep track of the narrative thread. I start the event and ensure completion. The 'in-between' is created together with the other (s) and has no fixed pace or place. I facilitate opportunities for people to enter the created context in their own time and to contribute to their own reality and possibility. I can play different roles in the event; I can assume the role of the narrator, the characters, or the props, whichever is needed. It is my intention to bring the various elements of the event to life in the here and now, so that everyone can experience the newly created reality and can co-shape it. My resources are the props, story-telling, singing, and playing.

I use the following techniques:

- I create an imaginary space through which we travel together. Within that space, there is room for everyone to contribute to the event according to their own attentiveness and perspective.
- I move along with what happens with or without words.
- I focus on the person, not the disease.
- I take my observations as a fact and use them as markers along the way.
- I am part of the creation. By assuming a context I can also be part of it.

3.4. How Does the Coach Prepare?

I prepare by focusing on the participants in order to enter the 'dementia play field.' I do not personally know the participants and try to imagine what phenomena may play a role. Although

I do not know their personal stories, I imagine the participants are people who wander through physical and mental space, losing their way and losing the meaning we give to the world; I imagine participants who are confronted with mortality and degradation processes on a physical level, but who also face these energetically and psychologically, and who lose hold of themselves and of their surroundings but yearn to find it again. I experience chaos, helplessness, and loneliness. I also feel the relief and the simplicity of just being there. This gives me an impression of the phenomena that people with dementia confront and soon, I will too, when I enter their reality.

The story of Jean Giono 'The man who planted trees' enters my mind (Giono 2005). A story about essential matters that is rich in images. It offers opportunities to 'play' together, with content, with language, with songs, with characters, with props. I am excited by what is offered me by this idea and follow my intuition.

A context begins to form within which I can offer the story. I search and find what assets could possibly be used. I know of myself that if I have a number of concrete objectives, I'll find my way. This context creates a space in which various possibilities for my encounter with the participants can coexist. I have the story, my songs, drawings, and props as a guide and set out with my suitcase. I do not know what to expect and how it will go. When I arrive on location, I experience the excitement of what is to come. Then I literally cross the threshold of the living room into the situation as it is in that moment: a living room with a table and four people around it, in bed another man, all of them in their own world.

The preparation is completed and the event has begun!

3.5. How Does the Coach Orient Himself? How Does He Tune In?

I *orient myself* by stating my presence as I step into the unknown. I commit to the other people by shaking their hands. I commit to the story and the context in which the meeting may come about, and in which it will unfold. Besides the audibly and visibly apparent activities, I listen in a different way to: how it goes, what and who moves, the pace of movement, the atmosphere, whether we are in the same space together or in different places, whether the others participate actively or not and how. I observe whether the space becomes fuller, more energetic, vibrant, cleaner, more awake, whether it triggers stress or relaxation, or whether there are fun elements. When you look to the event from the outside, it may seem that nothing is happening. When you open and allow

yourself to detect smaller and finer changes, it becomes quite clear that a lot is happening. You can observe how everything is constantly changing; how eventually the energy runs out, signifying the end, not because time has run out, but because we are filled up and are fulfilled by our common experience. You notice how silent moments occur, how one of us picks up the thread with a word or a song, by attentively touching or investigating an oak leaf. These observations help me orient myself in the situation.

As I *tune* in to the others and at the same time keep the story's thread in mind, I can perceive how people move in relationship to the others and to the subject. The gentleman whom I can hardly understand or reach inwardly moves towards me as well as towards the story. I notice he is more and more present. His attention emphasizes the collective reality. Through his inner activity, he breaks out of the inwardness of his secluded world. This changes the quality of the space in which everyone exists. As each contributes in his/her own way and at his/her own pace, the group begins to connect on progressively deeper levels and the individuals begin to connect with themselves, with each other, with the subject, the sounds, the words, and the content of the present moment The connections are not equally logical or easy to explain for me, but I perceive that they are valuable, not only for these people, but also for me. As long as I just perceive, I can stay present with the others and with what transpires organically during the session. Through this event and this deep exchange, I understand more about non-verbal communication and about *being* human. It is a mutual giving and receiving.

Now, eight years and a lot of practice, research, and field tests later, which have all increased my awareness, I would say that I tune in with my instrument of perception. Through my senses, I collect information about the complex situation in which I find myself. By tuning in with the environment and the other people in it I can orient myself. The present reality constitutes of four levels; the available space and props; the timing; the other people; and the all-encompassing whole of the reality: I cannot describe this latter complexity with words, but I experience the reality as in a holistic way. This subdivision of *different levels* of the reality provides me with an entry point to contact people with dementia: they play their instruments and are not themselves their instrument!

Everyone has an instrument at their disposal with which to observe the world and to express themselves. Each of us continually uses this instrument of observation to create, research, and give

meaning to the reality in which we live, independently, uniquely, and individually.

This instrument is particularly crucial, along with a research attitude, not only in the daily contact with people with dementia but also in training people who live and work with demented people. It helps to transform fixed ideas, judgments, and static beliefs. These hinder perception and blur the prospect of the here and now (being in the present). They tend to always revert to the beaten path, the familiar groove, and do not hear what is being asked for. These hitches become very visible in the contact with demented people. I need orientation, fine tuning, flexibility, and creativity to navigate through the chaos around me and find my way with the information I have at my disposal. When you understand and practice this, it becomes particularly helpful in developing your instrument of observation and in letting go of old patterns and images. When searching the way in unknown and uncertain terrain with people with dementia, this perspective supports all who are present.

3.6. How Do Coaches Know Whether What They Do is Right, Useful, and Correct?

The context in which I proceed is complex, constantly moving, and changing, and within it, I encounter chaos and uncertainty. Those with whom I 'travel' during the event have disruptions or defects in their tool for observation and expression. As such, a few facts are a given:

- there are players: four people around the table, one in a bed, and myself;
- we have tools at our disposal: the walls, the furniture, the props, our bodies, voices, etc.;
- we have a specific time span in which to work: 45 minutes;
- there is a physical space: the living room of a small group in a nursing home.

I use my observations and can implement my actions. Here I take responsibility as an individual. To be honest, I am not sure that what I'm doing is right, useful, or correct from an objective standpoint, but I can perceive whether the atmosphere becomes peaceful, harmonious, energetic, attentive, alert, contented, and whether the activities we do together are satisfying. When everyone sings along or is attentive or seemingly does not participate but unexpectedly hums at exactly the right moment, success seems self-evident. I can perceive how the space becomes full and the people, however deeply demented, start to beam. These qualitative measures fail to point to quantifiable achievement, and yet I unequivocally give this the qualification of making sense, being right, feeling correct. The core of the challenge is really to deal with the uncertainty and to give what I can provide from who I am as well as from my abilities and my talents.

3.7. Rules of the Game

Along with several colleagues, I have formulated some rules over time, which seem to work. These rules are based on being there, in the present, in the situation/experience of the event.

- *I stick to what I have actually observed* as my first impression of the situation. I use this as a guideline for my actions without trying to interpret it or making it personal. Whenever I do not adhere to this principle, I revert to a fixed pattern or idea and my perception becomes deflected or colored. That throws me off course as I facilitate the event.
- I trust my intuition, even though I do not know at the time what I'm doing or going to do.
- *I do not want anything from the others*. Everyone is free to participate or not in the activities. The activities offer a temporary basis, environment, and context through which we can meet. What this may mean to the others and what they may do with this experience, the event, is not for me to decide. I act freely and attempt to create as positive an event as possible. If I am willing to connect with the others fully in this context, I can give all I have to give. That is my limit as an individual. If this proves insufficient within the required standards, the situation needs to be approached in a broader context or the standards need to be adapted to the reality. However poignant and painful the inability to meet and understand each other may be, it is no excuse to use force or intimidation. It is a call to the coach to work with this inability. In addition, people with dementia are not able to contribute to a 'healthy' situation. They experience the chaos, the disintegration of existing structures twenty-four hours a day as they continually deal with their inability. Therefore it is up to me to take on the activity, the event, and not to expect anything from the others.
- I move along with the energy of the group. The more flexible I am, the less I stand in the way.

3.8. How Does the Coach Act in Accordance with the Context of the Event?

One example: I find myself telling my story differently in different contexts. I may introduce repetitions or rhythms, or emphasize certain phrases. This creates the common ground for our meeting in this moment. I note that I recite certain parts of the story in much more detail than

originally described and skip other pieces. It is as if the people who are present cause a shift in what matters, here and now, within this context.

Because I do not cling to a form, but rather let the timing and the rhythm emerge organically from the meeting, an event is created in a living context with an inherent wisdom all its own. In this way, the 'how' of the event happens independently of me; I simply stay present to accommodate to it. In brief, I act from the context, and that fulfills all of us.

4. Finding Self in Image by Mieke Merckx

4.1. Introduction

After thirty years' experience as an art therapist, I realize that each time I start to work with a client I embark on an adventurous journey with an open ending, much like the medieval bard or storyteller of yesteryear. The experience and skill I carry with me determine the outcome of the unexpected chances on the path I walk. The walking stick used in this chapter is the human capability of picturing their experiences. The road is not determined by the goal, but by what is done to get there.

Logic will get you from A to B. Imagination will take you everywhere.

Albert Einstein

4.2. The Reality of the Image

I pick up Ms. F, resident of the psychogeriatric department, with the wheelchair to take her to the therapy room for the first time. She is physically healthy and there is not much wrong with her... except she screams, all the way, in an incomprehensible language, confused, panicked, and frightened. On the threshold she pauses for a moment: she takes in the space. When we sit at the table and as I prepare the paper, she questions constantly, in an unintelligible and sometimes moaning tone of voice. I try to reassure her, to explain why we are here and what we will do. Nothing helps. In some desperation I grab the brush and start to paint a sky, the sun, a house.

In children's drawings, the house is a symbol of the body according to research that

we did a few years earlier. The sun is the symbol of the I, the clear self-awareness that people have.

Ms. F slowly quiets down as this all becomes visible, and looks closely at the painting. Then she gives a sound and grabs my arm. I look sideways at her and she takes the brush from me. She dips it in blue and draws a line from under the house to the sun in the sky. She looks satisfied: it is good. I bring her back to her room. Before I can pick her up for another session she dies unexpectedly. Back to the sun! (On the cover of this Companion is a copy of her drawing)

Images exist in two worlds and mediate between these worlds. When someone paints a picture, even just for themselves, it means that some invisible entity that existed in only inside them makes its appearance in image form in the concrete, visible, and tangible world. Images can convey messages in a simple way: they communicate something.

An important aspect of visual design is the art of leaving out the unnecessary to enhance the message. When body functions decline with age or illness, images can still teach, help process events, and mature in the world of the psyche. The soul can become more free. This creates an experimental playground for discovering, experiencing, and mirroring individuality and uniqueness.

4.3. Basic Principles in the Work with Elderly People with Dementia in Advanced Stages

Consciousness and memory of the here and now decline further in demented elderly at later stages of the loss of the I-experience. At the same time, while it does remain present, awareness of who one is or has been drops to the deeper layers of dream- or sleep consciousness. In unpredictable and astounding moments and in terminal lucidity (Chapter 14.2.) consciousness may become bright again.

When the therapist takes seriously the idea that there is always some form of awareness does that activate the demented person's consciousness? What does that mean for the therapeutic approach of the person with more advanced dementia? What role can images play as developmental potential?

I have found that, in order to establish direct contact, the therapist must step out of the reality of the here and now and attempt to set bias and preconceived notions of the history and diagnosis of the patient aside. The therapist may enter the encounter with an open mind and childlike curiosity about who the other person is. The open-mindedness increases the ability of the demented other to let a clear self-awareness appear, more often and faster than expected. The open-mindedness is to include that the meeting is not in vain, and that therapist and patient can each mean something to the other.

4.4. The Attitude of Open-Mindedness

The nursing staff ask me to go by Ms. G's room. She is bedridden. I do not know her and do not know anything about her, but something is seemingly needed. I walk over to her, go softly into the room, and stand at the foot of the bed slightly to the side, so as not to be too confrontational. I have a cart with painting supplies and a board with a very large sheet of paper that I can put vertically on the bedside table. When my paper is ready, I try to feel while painting what colors are needed or what is being be asked for. I try to experience the mood; then I put the brush on the paper.

Delicate hues create new shades and very slowly more contrasts emerge in the silence. A form appears spontaneously: a bird cage with a bird in it. When it is finished and the image can grow no further, I quietly roll the table out of the room and close the door gently behind me.

A woman comes up to me. She appears to be the daughter of Ms. G who comes to visit. She says, "Ah, you were at my mother's ..." I respond: "Yes, she is quietly lying in bed...." She gets ready to enter the room.

"Hey," she says, when she sees the picture "that is my mother's birdie... her darling .. she had a bird in a cage just like that ..."

The *open curiosity* that small children still possess characterizes the attitude of the therapist in the above case study. This attitude can create a safe and responsible relationship based on equality between demented people and caregivers.

When the ability to make abstractions declines, nonverbal actions may intensify the encounter.

Before the newborn can express himself in language and speech, communication takes place through observing, imitating sounds, and perceiving and mirroring of images that come from the environment. According to Winnicott (1971), mothers with babies on their arms naturally reflect facial expression or sounds of the child and vice versa, so that the baby gets a first experience of self-consciousness. A similar reflective contact with demented people comes about by connecting with their gesture, meaning, and mimicry. It results in a sense of security that is important in the developing contact. Carrying out repetitive motions can also help to establish or deepen the contact. Open-mindedness of therapist and patient in the above case description made it possible that the familiar birdie in the cage be created for Ms. G.

This type of 'mirroring' was researched in connection with non-verbal, deeply mentally handicapped persons. This resulted in unexpected communication with these people from a totally normal consciousness for shorter or longer time periods. It seems as if clear self-awareness can appear as if it were normal for just moments, like it also seems to occur in terminal lucidity (Chapter 14.2.).

Images can be used as transitional objects, similar to how in infancy contact may be created via a bear or stuffed animal as a safe mediator between environment and child (Winnicott 1971). In the use of images as transitional objects it is of course important to realize the difference between children and the demented elderly.

4.5. The Therapeutic Relationship and the Encounter With the Patient

I pay a visit to a woman who is terminally ill. Ms. H has been unresponsive for days, lies with her eyes closed, and seems to sleep quietly. We have had no therapeutic contact before. I softly enter her room, focused on the atmosphere around her and try to be there as a receiving vessel. I start to paint inwardly, not moving outwardly, in silent concentration. At a certain point, after some time of working on my inner painting, I notice from the corner of my eye that Ms. H is gazing at me intently, wide-eyed; she is totally there. I concentrate more on the inner painting and finish it. When I leave the room quietly, I notice her looking at me with those wide-open eyes; she makes a small whimper in recognition and then closes her eyes. She dies two hours later.

Every human encounter provides the opportunity for reciprocal development. For the therapist, it is important to remain focused on the clear self-awareness of the demented person. This gives an opportunity to see the person behind the illness and to communicate full-fledged despite the impediments that dementia presents. Working with dementia from this perspective also opens other opportunities than simply the direct response to challenging behavior. It gives the possibility for a mutual experience of mature, full human contact. To make it happen, the therapist is to leave everything behind and receive openly what will appear in the moment.

4.6. The Significance of the Image

I walk into the living room of the psycho-geriatric ward. At the large table and also scattered in the room sit a few people. It is essentially silent. The staff has its coffee break. I quietly moisten the paper on large board and prepare for what comes. I have my back turned to the people so as not distract them with my watching or unconscious response. I am standing somewhat aside from the board so that the paper remains visible.

Every now and then someone will look up momentarily to then again gaze silently out the window or into space. I start to paint on the lightly damp paper in large, bright hues, as yet very thinly, so anything can grow, a thin blue color. I continue to listen attentively, and slowly more people watch and keep looking. I take care that my painting gestures keep flowing. Suddenly, a man starts to tell that he used to go on holiday to the sea. I take that into painting. Someone else reacts and that too appears in the growing image. A woman at another table loudly responds telling a memory. It also gets a place in the painting. The special painting technique with damp paper and diluted watercolors allows for something to appear and then be changed into something else. The conversation becomes livelier as people exchange gazes; a group is created.

The cleaner halts, smiles as he stands watching, leaning on his stick with cleaning cloth. I actively involve him in the process; he is a seasoned quiet friend of everyone. I speak for the first time and ask him: "John, what swimsuit did you wear as a kid when you went into the sea?." He replies, and the swimsuit is painted. Everyone smiles at

him. The picture continues to grow in the interaction until it is 'done' and finished. I sit down for a moment at the table to listen to the lively conversations. The collective painting is displayed next to the table. There are many picture elements that have appeared and then disappeared, which lends depth and colorfulness. Meanwhile someone from the staff comes by now and then to share in the liveliness of the group. Then I quietly roll my cart out of the room and leave behind a company that is still engaged in vivid memories. Some people walking or wandering in the hallway want to see what is on the trolley and I say: ... "we went to the sea, on vacation ..."

The starting point of images is in dream consciousness. Images move between feeling and sensing awareness. A person with dementia who is in a vegetative state can be addressed in his/her dream consciousness through images. The awareness of the demented brightens and he/she becomes realized as a person, as a Self. Images awaken a form of communication anchored in early childhood.

5. Where Words Fail, Music Can Speak by Connie Alblas

5.1. Introduction. About Music and Music Therapy

Music is movement, an invisible, intangible phenomenon that takes place in the present moment. As soon as the sound of a musical phrase is heard, it is also over. Music immediately effects people because it always takes place in the here and now. And it does not stop there. The musical experience also has a sequel; it awakens an element of motion in people; it touches them. Their cheeks may have reddened, they may feel like dancing or feel relieved because tears can flow more easily through the music.

Unlike the eyes to the light, one cannot just close the ears for sounds or music. Stated simply, music enters our being physically, emotionally, or rationally. No part of us can be shut off from the influence of music. Most everyone knows the fluttering feeling in the stomach or heart region as the body resonates certain musical rhythms or the goose bumps when listening intensely to a song. Other examples include the effect of the soft, penetrating sound of singing bowls or the deep resonance of a kettledrum. Sounds literally consist of vibrations in frequencies that we not only hear with our ears but also perceive with the rest of the body.

It is precisely this physical sensory quality of music that makes it suitable for use in nursing homes.

5.1.1. The Potential of Music Therapy

When listening to music, different types of experiences can occur depending on the type of music. In music therapy this falls under the heading of *impressive* or *receptive music therapy*. There is a movement from outside to inside: the therapist plays, sings, and hums a song or plays a specially tuned piece of music for the client with the aim of creating inner movement.

The movement from inside to outside is called expressive or active music therapy. This involves

bringing out what lives in the person. I find it very impressive to see how someone with dementia may be able to express their feelings by playing the marimba or timpani. As a rule, receptive and active moments alternate several times within one music therapy session. Receptive music therapy becomes more central as the dementia progresses.

Music evokes forgotten memories or incites movement. Musical memory is long retained in life, and music can offer comfort and relaxation until the last stages of life. Music and singing may be valuable ways of making renewed contact with family and friends when they can no longer verbally communicate with their loved ones. Singing takes an important place in psycho-geriatric music therapy. It appeals to the breathing, exercises the voice and the facial muscles, and stimulates communication. The elderly person becomes inwardly active by having to search for melody, pitch, and text. Many people who have difficulty speaking are amazingly able to sing many verses of a song from their youth with ease. These are important success moments for someone with dementia. In the words of a client they are for a moment 'their old, own self' again. People cheer up by singing, and radiate because they can form words and communicate with their environment, which is crucial to the human aspect of community.

"My father strongly regresses. It takes all my mother has to get him out of bed to go to the day care facility. Except on 'choir day': on 'choir day' my father jumps out of bed and is ready before the taxi arrives."

Singing in a group is a powerful impetus for social life. Group members share emotions by singing together. Singing creates a sense of connection whereby relationships are initiated and strengthened. Within the institution we have set up a choir for people in different stages of dementia. Outside choir time, the differences again become visible, while singing they are almost gone. Singing in the choir is beneficial for the sense of commitment to the environment. And this choir not only performs the old familiar songs; it sings new songs with no trouble, claps rhythm pieces, and combines movement with vocals. Working towards a small performance for family members adds an extra dimension and gives meaning to the practice. *"We do something in return"* mentions one participant.

5.1.2. Music Therapy and Science

Although music therapy is centuries old (early peoples sang to their sick, played instruments to drive out diseases or prevent them, etc.), in the modern Western world it is a relatively young science (Smeijsters 2006). Although much is known from experience and many of its aspects and benefits have been described, little has been scientifically researched. However, despite this shortcoming, music therapy has acquired a solid place in nursing homes because of its obvious and beneficial effect on people. In recent years, more scientists have become involved with music in care situations and further investigation into the relationship between music and the brain has been conducted. (Finch 2013).

5.2. Defining the Problem and Diagnosis

5.2.1. Outpatient Care and the Stage of the 'Endangered' I

Recently, Ms. I started coming to the outpatient clinic. She participates in the music therapy observation group along with five others. Ms. I is 84 years old, lives alone and, with the help of her daughter, a domestic aid, and a meal service, she can still maintain a relatively normal life. She knows that she has Alzheimer's and is afraid of what awaits her. She realizes that she is already rather forgetful. This gives her anxiety and sad feelings.

During the music therapy Ms. I turns out to be a natural leader. Even though she has never played music, she guides the music of the instrumental improvisations in the direction she wants. She does this by constant listening, refraining, then play more dynamically, sustaining, accelerating, or slowing down. She thoroughly enjoys the compliments she receives from the other group members who feel supported by her: "We hold on to you." She herself puts it as follows: "I will do anything to keep good as long as possible. Puzzles, gymnastics, exercise. This being-together in music is, however, food for my soul. I'm not just a sick and gloomy woman!" When I sing an Irish song for her because she has chosen it for her birthday song, tears roll down her cheeks. "Can you promise me that when the time comes, and if I happen to find myself in this house, you will sing this song for me? Even though I will no longer know you?" I promise.

In the weekly, six people music therapy group, I follow a more or less well-defined program. Clarity increases confidence in the program and allows participants to willingly continue to participate and dare to try out something novel. In my program is always 'something new', ranging from a special instrument to a Chinese song. It aims to stimulate the patient's curiosity and often initiates a conversation that provides insight into preferences and things that arouse aversion.

5.2.2. Stage Two: The 'Stray' I

The specialist in geriatric medicine requests that I observe Mr. J. Mr. J is very restless, continually walking around in the ward, and exhibits claiming behavior towards staff, visitors, and fellow patients. Hardly anything is known about Mr. J. And the caregivers cannot find the right approach to give him trust and support.

At the time of the referral, Mr. J has been in the nursing home for six weeks. He is 76 years old, a large guy. A few weeks before admission, he was found traveling, in a confused state, in his slippers, and without any luggage, on the train to Utrecht (about 50 miles away). The police reported that Mr. J was anxious, could not tell why he was there, where he was going, or how he got into the train. What followed were the police office, the crisis team examination, provisional housing, the diagnosis of Alzheimer's disease, and eventually admission to the nursing home.

Mr. J's life is a mystery. Whether he has a wife or children, friends, what kind of work he has done, etc. is all unknown. Mr. J sometimes has to search for words, but his speech is relatively clear. He can, however, not relate anything about his past. He pauses and nods in response to questions about it. His address has become known a week ago because a worried neighbor inquired to the police. Unfortunately, the neighbor also cannot tell much about <i>Mr. J's past; they only have known each other for eighteen months and sometimes watched soccer together.

Our First Meeting

We meet in the hallway of his group home. As soon as I introduce myself, J says: "Ha! You are from Rotterdam! I can hear it in your accent!" Standing in the hallway, Mr. J tells about the docks that he finds so beautiful. I affirm the beauty of such a view, that I also like the water myself and the smell of the harbor. Then I start speaking/ singing 'Ketelbinkie' (an old Dutch sailor's song). It appears that he knows the song well, singing with qusto, his arm movements supporting the text to the end. Mr. J's eyes are sparkling now and his face has regained some color, he stands next to me upright, laughing. After this initial meeting more encounters follow. Gradually, we can sit down in his room. Several songs and instruments evoke important memories in Mr. J. The harmonica brings good memories of his mother. Rotterdam remains a big topic, the water, the ships, etc.; he seems to know quite a few shanties. Mr. J describes his father as a 'drunkard.' Confused stories of beatings and drinking come up, accompanied by tears and anger. J cannot rationally process these memories, but they come up repeatedly for him as if he, is stuck in them. Improvising together on the drums helps to bring out the feelings of being misunderstood in motion and sound. "Yeah, there you go, there you go," he can call fiercely as he beats on the djembe. Then he can burst into laughter. Musical play on the xylophone will subsequently bring Mr. J back to the here and now, to a positive situation, a friendly song, and a smile. Music therapy does not reduce the unrest of this patient immediately, but during the sessions, a lot of useful information about Mr. J's life comes to light. Singing the songs that are meaningful to him instantly creates a positive connection with Mr. J. This gives the care givers a tool to respond better to his agitation. Ultimately, this allows for more respite.

The reason for referral to music therapy can vary. Geriatric medicine specialists refer people for behavioral problems such as agitation, aggression, wandering, or mood problems. I usually choose to first leave the problem for what it is and enter the encounter with an open mind and heart. When I respond to what occurs in the moment, connect to the situation in the here and now, then the clues for a 'musical diagnosis' and possible further therapy unveil themselves naturally. Often other issues come to light as in the example of Mr. J. By targeting what is healthy, I work via a detour towards mitigating the original problem. Everyone caring for people with dementia

should have a basic package of suitable songs, with an explanation for when to use them in their repertoire. It is an additional possibility of communication that in my opinion cannot be missed when you care for this group of people.

I have known some of these individuals for many years. They often come to the day care shortly after their first 'gut feeling' that there is something wrong and the diagnosis dementia is set. These people and I know each other in an unusual way, i.e. we mainly meet each other musically. Joy, emotion, sadness, it all passes by in those years, always linked to music, song, or sound. We share the same musical world weekly while the process continues, sometimes very slowly and sometimes more rapidly. At times, it is difficult to see how people with whom you enter into such a deep connection, irrevocably slide into increasing dementia, sometimes desperately fighting against all the losses they suffer. On the other hand, I experience it as a special privilege that I may accompany them in some way on this path. What touches me is that we, music therapists, often are more or less 'recognized' for a long time. Not by name or position, but when I meet someone after a long time in a living room somewhere, they may suddenly start singing or conducting.

5.2.3. Music in the Fourth Phase: The 'Receded' I

As I walk into the hallway of her unit, I can hear Ms. K screaming. Upon entering her room, I also hear a nasty hum; this appears to be the (empty) refrigerator. When I greet her, Ms. K screams even louder. She turns away her head with closed eyes. I unplug the fridge, the humming stops. Ms. K also stops screaming.

So as to accustom Ms. K to my presence, I start humming softly some meters away from her still. When she cries out rather loudly, I stop for a moment. After a while, the sounds change, becoming softer with intermittent sighs. I dare come a bit closer. I lay my hand on her hand humming all the while. She lets me do it. I keep humming and gently stroke her hair. She releases a deep sigh. Then I put a singing bowl at her feet and strike it gently. Ms. K turns her head. She opens her eyes and they wander about. I show her the singing bowl and strike it again. Ms. K watches, following the movement of the paddle on the bowl. She is silent, watching quietly. After a while, Ms. K closes her eyes again. I sound the singing bowl a few more times and then remain sitting beside her a while longer in silence, holding her hand. As I slowly withdraw my hand, Ms. K grabs it and pulls it to her mouth. She gives it a kiss.

When someone is in the final stages of dementia, I change my approach. At this stage it is helpful to know a person's musical taste, their musical history. I have usually changed my approach already before people come to the final stage since the phases are merely a theoretical framework: I move along with the changes I perceive in the clients. Often this involves fostering an environment of relaxation. People can be restless or cramped by the encroaching darkness of their own mind. They themselves cannot say what they need; rather they require others to interpret their language. Working with delicate sounds such as the singing bowl's or a lyre is suitable to this stage in patients.

5.3. Silence

Ms. L wants to die. That is a problem because, as she says, no one wants to help her. Maybe I will help her...? I have put my instruments back into the corner. The Chopin CDs that she used to love are back in their cases. No sound, no song, no rhythm can distract her from that one thought. Whatever I try, nothing pleases her. Ms. L is a 97 years old lady. She wears only costly apparel, and today, she wears a beautiful cashmere suit, which has long since become too big. She has traveled the whole world, lived in several countries, had a large circle of friends, was engaged in photography, and was a board member of several foundations. She says she has had a wonderful life, "rich and full of love." All that is over now. "There is no one left. No one at all, can you imagine?" I try to imagine a situation like that in my life-one devoid of friends and loved ones in which no one knows me, no one shares my history, and no one calls me by my nickname. I try to envision a life in which strangers surround me, taking over my processes and decisions because I can no longer do those things for myself. Yet there is something that is even worse than this and Ms. L mentions it: "And now I also lose myself." I have no reply. We sit in silence together for a while. Ms. L puts her fingers on my sleeve. Then she suddenly says, "Thank you, this was rather refreshing." A radiant smile.

Back home I come upon the statement by Tao Meng: "... silence is the deepest sound." Silence was the only sound that could help Ms. L today.

Because of silence, music can flourish. The moments of silence in music—the rests—give it power, shape, and expression. I see this as an analogy for life itself. Could we ever come to ourselves, exhale, and relax without moments of silence? The meaning of silence is comprehensive.

End of Life Care and Dementia by Marie-José Gijsberts

You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.

> Dame Cicely Saunders, founder of the modern hospice movement (1908-2005)

6.1. The Therapeutic Approach during the Four Stages of Dementia

6.

The four stages of dementia (Feil 2010, Verdult 2003) are summarized in this chapter and specifically brought into focus with the changing demands of the demented person for support from the environment.

6.1.1. Approaching the Patient in the Cognitive Phase: The 'Endangered' I

The person in the first phase of dementia, the cognitive phase, may be well aware of his/her deterioration, as described for Mr. E (section 2.2.). The environment can be supportive at this stage by *calling on the accessible cognitive abilities* of the patient. This enables the person with dementia to function as independently as possible. Support from the environment in the first phase of the dementia process consists in particular of helping oversee situations *(comprehensibility)*, so they can be understood by the person with dementia. Often, with a little help, the demented person can himself find a solution (*manageability*), which promotes the feeling that he/she is still important *(meaningfulness)*. This allows the person with dementia to experience *a sense of coherence*, despite cognitive limitations. This sense of coherence allows the person with dementia, despite their limitations, to experience the world and the environment as understandable, manageable,

and meaningful (Antonovsky 1979).

This delicate process relies on the willingness and ability of caregivers to provide the needed assistance such that it coincides with the cognitive abilities of the demented person. This can be a touching adventure for all concerned (Geiger 2012).

This approach in part also applies to the second phase of the dementia process: the emotional stage of the 'stray' I. In many nursing homes, family members or friends are asked to write the biography of the patients with extra attention to events that have been of special significance for them. This may aid the appreciation of the patients' behavior.

6.1.2. Approach in the Emotional and Motor Phases: The 'Stray' I and the 'Hidden' I

Naomi Feil calls the methodology recommended in the second and third stage of dementia *validation*. People in the environment are challenged to understand the expressions, feelings, and needs of the person with dementia, and to validate and fulfill them. His or her experience mainly entails old memories. Conversation becomes more difficult (see Chapters 3 and 4). This stage demands other than cognitive skills to understand the demented person. Empathic abilities and insight into the world of the patient are important. It is helpful to know the biography of the patient (see the story of Mr. J in section 5.2.2.). This forms the basis of experience-oriented care.

6.1.3. The Approach of the Sensory Phase: The 'Receded' I

In the fourth stage of dementia, the sensory phase of the 'receded' I one can still have good contact with the demented person, albeit mostly in a non-verbal manner: loving touch, music, an intentional regard (see Chapters 4 and 5), etc. Experience-oriented care is also part of the package.

6.1. Legal Competence

The four phases of 'dissolution' of the I-awareness are also important in recent developments regarding mental and legal competence of people with dementia. Demented people appear "... to

be involved in their situation much longer and more intensely than previously assumed. The process of dementia does not mean that the person's ability to appreciate his/her life situation and what is important in it for him/her directly and absolutely falls away" (Hertogh & Verkerk 2002). Jaworska (1999) advocates relying less on the cognitive model of *decisional capacity*, but rather on a concept in which mental competence is defined in terms of the ability to appreciate the personal situation *(the capacity to value)* of the patient. This implies that things are discussed in such a way that it matches the capabilities of the demented person and gives him/her the opportunity to express himself/herself as much as possible. Hertogh and Verkerk (2002) express this in a distinct way: "This care is aimed, so to speak preventively and by way of auxiliary, to situate the surroundings in a way that the person with dementia acknowledges himself as a competent actor in a situation that he experiences as safe." In the current dementia care, this process is called *Shared Decision Making* (Godolphin 2009). Open communication about the possible course of the disease contributes to quality of life of the demented person (Soest-Poortvliet et al 2011). Experience confirms that this is possible well into the dementia process as long as family members, caregivers, and the responsible physician ask their questions with a sense for the experiences and abilities of the person.

6.2. Palliative Care

Palliative care and treatment for demented patients is specific for this patient group. It may mark the end of the fourth phase of Verdult or Feil, but can also occur much earlier (see Table 6.2.). A small number of people with dementia die in the final stages of dementia. The goal of palliative care is generally to improve the quality of life—of patients and their families through prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO 2013). Palliative care has evolved from the discipline of oncology. Other conditions than oncological disease, such as organ failure and dementia, have different symptoms, and take a different course. The latter have recently received more attention (Janssen 2012; Vilans 2013). In the last few years, palliative care in dementia in general has been given more consideration. The European Association for Palliative Care (EAPC) published an article in 2014 with recommendations for palliative care in dementia, which focuses both on symptom control and on meaning and religious aspects of care (see link EAPC).

6.3.1. What Do We 'Know' about Dementia at the End of Life?

We may distinguish two types of expert knowledge:

- 1. The first form of expertise is obtained through empirical-analytic research. The tables with the general problems in the last stage of dementia are obtained through this method. It allows us to make statements about dementia in *generalized* terms.
- 2. In addition, expertise can be acquired in relation to the specific characteristics and the development of symptoms in one unique person. It allows us to make statements about this *individual* person's unique and meaningful experience of dementia.

Both forms of knowledge are each one side of the coin: general patterns and individual processes.

The following *general* problems may occur in the last stages of dementia:

- Problems *eating and drinking*. Pasman et al (2004) showed that the quality and length of life will not improve with artificial hydration and nutrition in the final stage of dementia. Loved ones of people with dementia often have questions about this. It is important and often reassuring for them that the person with dementia does not suffer from gradually eating and drinking less, and to know that this pattern is commensurate with decline in dementia.
- *Pain* may be expressed differently in the final stage of dementia. Under similar circumstances. non-demented people use more pain medication (Marzinski 1991). Pain is probably under-treated in people with dementia. People with dementia likely do experience pain but cannot interpret it cognitively and respond instead with a change in behavior (Scherder et al 2003). Since demented persons have problems communicating their symptoms verbally, non-judgmental observation is important. Interpretations as "Ms. Y is unwilling" or "Mr. Z resists" are not in line with compassionate assessment. Demented people probably experience more pain due to damaged connections between different areas in the brain, for instance in Alzheimer's disease (Scherder et al 2008). Demented

patients with unexplained agitation who receive pain medication make more contact with their environment and are more active (Chibnall et al 2005). Measuring instruments like the PACSLAC-D, PAINAD, and REPOS may be helpful to interpret behavioral changes (see Table 6.1.). A score of 0-1 in the table indicates that there probably is no pain. Score 2-3 means mild pain and a score of 4 or higher indicates moderate to severe pain. In the latter two scores, pain medication must be considered. The PAIN-AD can also be used to evaluate the effect of pain medication. The score lowers with effective pain relief.

ITEMS	0	1	2	SCORE
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level of speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimacing	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid Fists clenched Knees pulled up Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
			Total	

Table 6.1. Pain Assessment In Advanced Dementia - PAINAD (Warden, Hurley, Volicer, 2003)

BOLK'S COMPANIONS

- *Pneumonia* occurs more often in people with dementia because they have more difficulty swallowing. There is a significant relationship between contracting pneumonia and death from dementia. Even when treated with antibiotics, 50% of these patients die within six months. Antibiotic therapy on the other hand increases well-being but also prolongs the terminal phase of life (van der Steen et al 2002). A scorecard was developed for estimating the risk of death within fourteen days in a demented patient with pneumonia and antibiotic treatment (see link EMGO). This may be helpful in the *shared decision making* between the person with dementia, their loved ones, and the physician.
- The brain of people with dementia is vulnerable and therefore more easily subject to metabolic dysregulation. Minor problems like constipation or a urinary tract infection may lead to *delirium*. The symptoms of delirium are confusion, increasing disorientation, agitation and hallucinations, or extreme drowsiness. The better one knows the demented person, the easier it is to see that he/she is different from normal. Treating the underlying condition often causes an improvement in these symptoms within days or weeks.
- Only 14% of demented persons reaches the last, sensory stage of dementia, when the I is 'receded.' *Specific features of this phase* are: a complete loss of the ability to stand and walk, incontinence, few or no communication possibilities, feeding problems due to reduced food intake or as a result of problems swallowing, complete dependency on care, and repetitive motions such as fidgeting or sucking. Complications of this phase are pneumonia, pressure ulcers, contractures, and paratonia⁵. The causes of death are different for people who die before or during this phase (see Table 6.2.). During this stage, more than 50% of people die due to cachexia and dehydration. Wonderful methods were developed for nursing home residents in this phase to provide optimal care and establish non-verbal contact (see Chapters 4 and 5 and www.stichtingpdl.nl).

⁵ the patient keeps stiff in attempts to push him/her

Cause of death in % Research N = 890	Alive in last phase N = 126	Deceased before final phase N = 764
Cardiovascular disorders	13.5	22.1
Acute pulmonary disease	12.7	21.3
Cachexia/dehydration	53.2	32.2
Other causes	20.6	24.3

Table 6.2. Causes of Death In and Before the Final Stages of Dementia (Koopmans et al 2007)

6.4. Spiritual Aspects of the End of Life

The concept of spirituality is hard to define since it has a different, personal connotation for different people. Its contours can be described based on a broad orientation of spirituality at the end of life (Gijsberts et al 2011). This study enables us to embed the concept in a model which links it to other aspects of palliative care (see Figure 6.1.).

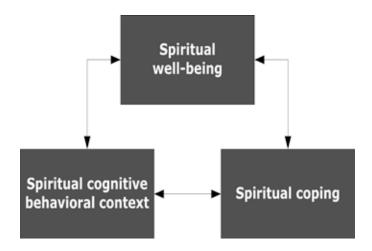


Figure 6.1. The dimensions of the concept of spirituality at the end of life

The concept of spirituality may be divided into three dimensions for consideration (fig. 6.1.). One of the dimensions is *spiritual well-being*. This dimension includes concepts that relate to 'what life means for a person in its deepest sense.' This will involve aspects such as: peace, harmony, trust, hope, acceptance, purpose, meaning, connectedness, completion of life, fulfillment, and consolation.

End of life care should be so designed that it contributes to the spiritual well-being of the person with dementia as well as that of his/her family and the healthcare professionals providing end of life care. Thus, people with dementia and their loved ones can harmoniously complete life and have peace with what this process brings.

The other two dimensions of spirituality can also contribute positively or negatively to spiritual wellbeing. *Spiritual cognitive behavioral context* refers to a dimension of the concept of spirituality that points to philosophical issues (beliefs and associated activities, such as prayer and meditation) and contacts that are related to the beliefs of the demented person (the priest, minister, co-believers, and also the relationship one can experience with God or a higher power).

Further contributing strategies to spiritual well-being come from the third dimension of spirituality: *spiritual coping*⁸. Coping concerns the way a person deals with challenges in life. Spiritual coping encompasses the entire range of human coping options, specifically incorporating spiritual resources. For instance: consciously praying the 'Hail Mary' four times a day may support the patient to be at peace with being ill or the prospect of death.

How does health care staff contribute to this part of the process? The results of an ethnographic study in a Dutch nursing home showed that the various disciplines do not communicate about spiritual issues in nursing home residents. Nursing home chaplains seldom participate in clinical meetings or discussions wherein he/she might have helpful contributions regarding the spiritual well-being of the patient in question. However, informally, the nursing staff often contributes much to the spiritual well-being of patients within the integrated care process (McSherry et al 2004). They support patient and family within the context of the cognitive abilities of the patient. As such, they together promote the process of completing life, contribute to a peaceful death of the person with dementia, and provide comfort to his/her relatives (Gijsberts et al 2013).

Part II Researching Diagnostic Criteria, Risk Profiles, and Prevention of Dementia

6

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Summary of Chapters 2-6 and Preview of Chapters 7-12

The preceding chapters have shown that caring for people with dementia relies on *practice-based* research by experienced therapists and physicians, often in direct patient contact, for its development. This practice-oriented method is especially important when questions about mental competence and palliative care arise. It also is clear from what was relayed that cognitive decline demands other forms of communication. The tentative conclusion may be drawn that *the person with dementia is accessible and can continue to develop into the last phase of the dementia process with the appropriate individualized therapies.* Acceptance of sensitive formative years' experience plays a particular role. During the dementia process, unresolved earlier experience comes up in the form of behavioral problems. The behavior of demented persons may also reflect childhood attachment problems. Caregivers need to connect with the current situation by using sensible tools to meet this behavior, often acting on the basis of intuition. Qualities such as *empathy, creativity, openness, curiosity, open-mindedness, and/or patience* are important.

Overview of Part II

Chapters 7-12 inform you about recognized studies on diagnostic and therapeutic options in dementia and the problems inherent in those modalities.

Chapter 7 describes the process of normal aging and compares it with the dementia process. It designates what is known of anatomical, physiological, and psychological changes, and the effect of biography on the normal aging process. Normal aging and the dementia process are surprisingly similar.

Chapter 8 talks about the classification, diagnosis, and prevention of dementia. The staging of the loss of the I-awareness proves to be an important starting point. Phenomenological⁶ diagnostics can contribute to the dynamic and unique processes of the demented person.

⁶ as seen in practice

Chapters 9, 10, and 11 attempt to delineate dementia.

Chapter 9 discusses the clinical diagnostic criteria and possible causes for the four main types of dementia, which concludes with a statement about the difficulty inherent in making an exact dementia diagnosis.

Chapters 10 and 11 deal with the various risk factors for dementia. These are grouped into four clusters, which we believe each represent a different biological system.

Chapter 10 discusses

- 1. (Neuro) anatomical, genetic, and epigenetic risk factors
- 2. (Neuro) physiological risk factors

Chapter 11 covers the other two clusters of risk factors.

- 3. Emotions and stress, inflammation, and changes in diurnal rhythms as risk factors
- 4. Circumstances and events from the life story as risk factors. A comparison is made between normal child development and its 'reversal' in the decline during the dementia process.

Chapter 12 provides insight into the background of the research method of this Companion.

7. Normal Cognitive Aging by Marko van Gerven

Being at work and interested in the world around you is the best medication against aging. Every day I feel like I'm born again, every day I start completely new, unreserved.

The cellist Pablo Casals at the age of 93. Kahn (1970)

7.1. Introduction. Normal Aging is a Healthy Process

Beginning with an interview with an older person, this section describes the healthy aging process.

Health is a difficult term to define because in addition to physical health, it also includes emotional and social components, and is constantly subject to change. Feeling healthy and strong can fluctuate considerably in a single day. Prolonged stress leads not only to the experience of emotional disharmony, tension, and poor sleep; it also affects physical and mental health. The physical environment also has an effect on health. A *healing environment* stimulates restorative processes (Brands & White 2013). Recovery after surgery is expedited when a patient has a view of nature from the hospital room (Ulrich 1984). To stay healthy, humans have to find a balance between the risk of disease and protective influences. According to Huber et al (2011): "Health is the asset to manage and adapt to changing social, physical, and emotional challenges and restoring the balance."

7.2. "It Could Be Over Tomorrow"

Mr. M is a personal coach and is 74 years of age. He is 1.82 meters tall and 80 kilograms. He is a vital, strong man with rosy cheeks. He is willing to tell his story, but is equally interested in the interviewer. He grew up in Friesland in a landscape

with wide horizons, water, and starry skies. One of his grandfathers had dementia. A younger brother died this year from lung cancer at the age of 69. His brother's death confronts M with the finite nature of life. Unsurprisingly, we come to talk about his physical condition. Unlike previously, he must care for his body actively. He experiences aging as an inner, opposing force, which is set to reduce his horizon and his activities. Were he to concede to it, he would quickly have a much more passive and sedentary lifestyle. He recounts the strategies he has found to counterbalance this tendency. What helps him is to keep up to date on current events. M reads newspapers in different languages to be able to view news stories from different perspectives. He wants to be present in the world and maintain a wide horizon. The latter is repeatedly mentioned as M refers to the landscape of his youth. Continuing his work as a personal coach, albeit at a lesser intensity, is also important to counteract the aging process. M recounts that when he noted that he became more uncertain when dismounting from his bicycle and he started to feel insecure on the deck of his seaworthy yacht, it seemed to him time to be more active with his physical health. He started going to fitness classes and visits the sauna two to three times a week ("I feel reborn afterwards"), watches his weight ("my belly circumference must be less than 1 meter"), and went to his GP to start blood pressure control with diuretics.

He notices that remembering new names or recalling familiar names or concepts can be disturbingly difficult. Keeping an agenda was never his strongest point and requires more attention now. When making appointments, he helps himself by making an inner picture of the person with whom he is to meet; then the appointment is easier to recall. The maneuvers needed in sea sailing are easy for him. He has no complaints about hearing and vision; at most he has become more sensitive to loud music.

After 9 PM he is out of energy and does no further computer work, but he does reads. He is more slow at this time of night. At half past ten he listens to some music and then goes to bed.

He is not sensitive to stress, but admits to being more emotional than in the past. This arose spontaneously, but also seems to be a result of comments from his colleagues who noticed that he never showed his emotions, which in turn prompted him to pay more attention to his emotional and feeling processes.

Five years ago, a meningioma⁷ was removed from his brain. He had noticed that he had short attacks of aphasia⁸. There were no adverse effects from the intervention. The principle that M lives by is that the situation he finds himself in belongs to him. His illness taught him to speak less and listen more. He compares it to pruning a tree: removing the less essential branches in favor of the important ones. He is accustomed to reflecting on his life and it is clear to him that he speaks more frequently about the past, mainly his childhood in Friesland. Practices that had their genesis in his childhood have condensed in the course of his life. For him, the saying of the Dalai Lama is guiding: the great secret of happiness is that humans accept their own mortality. "I live aware of the reality that it could be over tomorrow. How I am now is not only determined by who I was and what I did, but even more by the willingness to see my future as being in a never-ending learning process".

This chapter explores aging from four perspectives:

- 1. The life story;
- 2. Neuroanatomy;
- 3. Neurophysiology;
- 4. Neuropsychology.

7.3. Aging From the Perspective of the Life Story

The chief risk factor for dementia is *aging* (Lovestone 2009). This leads to the central question: how can humans live healthily? Two assets may be especially relevant here: *resilience* and *self-discipline*.

An example of **resilience** is the sense of coherence (Antonovsky 1979), referred to earlier (6.1.1.). The sense of coherence is not static; rather it consists of capabilities that can be used to successfully handle unexpected situations. These capabilities include the ability to oversee a situation *(comprehensibility)*, have the confidence to generate a suitable solution *(manageability)*, and most

⁷ a meningeal tumor

⁸ partial or total loss of the ability to articulate ideas or comprehend spoken or written language

importantly, the view that one's own contribution matters *(meaningfulness)* (6.1.1 and 11.2.2.). The risk of chronic stress reduces with people that have a well-developed sense of coherence. The sense of coherence is enhanced in the above case by the view of M that the release from the past is possible for him through acceptance of his own mortality. Acceptance of past events and the search for meaning and learning opportunities focused on the future can help reduce stress from the past.

Self-discipline at a young age is a predictor of physical health in adulthood (Moffitt et al 2011). Leading an *active social life* and *positive stimuli from the environment at a young age* are important for the mental health and the development of self-discipline. Feil (2010) quotes Erikson who states that each phase in life renders its own tasks. According to Erikson and Feil, the task of old age would be to gain *self-esteem*. When this fails because the 'emotional backpack' is too heavy, despair and depression ensue. The essence of dealing with the past is the activity of the 'I.' Healthy development in the early years of life and a successful dealing with this period lead to strengthening of the Self and less stress in later life. This is again related to less cognitive decline (Holmes et al, 2011).

The following questions surface in the elderly (Feil, 2010): how did I live my life? How did I deal with the challenges that came my way? Which unresolved emotions do I still carry along? How do I deal with loss and setback? Being in harmony with oneself leads to feelings of **integrity** according to Feil. Older people who have a sense of integrity have already done much of the emotional work of previous periods. Feil implies that feelings of despair and depression are related to incomplete emotional processing.

Another important component of self-discipline is related to the **childhood IQ**. This IQ appears to be a significant predictor of cognitive health. In addition, most older people appear to have a peak in memories for events from between 15 and 25 years. Memories of that phase and also of the early years of life are important when it comes to how the emotional backpack lightens over time.

In youth, brain development after birth runs parallel to successively the development of the *senses; moving and walking; social interactions* through speech; and *the development of thinking* (Lievegoed 1974, see also Section 11.2.4.). This lays the foundation for, respectively (Schore 2010):

1. Being able to reassure one's self (sensory development);

2. Developing procedural memory, which automates acquired actions such as 'knowing' how to bike or walk;

- 3. Developing social interactions through speech (source of the emotional memory);
- 4. Starting the development of biographical memory (development of thinking).

These four steps in brain development have a counterpart in aging. Developing biographical memory corresponds to memory loss in the first 'cognitive' phase (Feil 2010) of the dementia process, the phase of the 'endangered' I (Verdult 2012). The development of speaking through social interaction resembles the 'emotional' phase of Feil (the I 'astray'). Developing the procedural memory finds a counterpart in the 'motor' phase of Feil and the 'hidden' I. Sensory development is mirrored in the 'sensory' phase of the 'receded' I. At this stage, sensory stimuli are about the only way one can communicate with the demented person. This *reversal of memory development* compared to normal development during the dementia process will be elaborated in 11.2.4.

The above described older person M has been cognizant of several of these assets and has actively worked to develop them. This certainly has contributed to his good physical and mental health for which he so conscientiously cares.

7.4. Normal Aging from the Perspective of (Neuro) Anatomy

Undeniably the body deteriorates with age, including changes in cognitive abilities. Aging is accompanied by **cell loss** in the brain as well as shrinking neurons. There is also a loss of neurotransmitters and damage occurs to the genetic information (DNA), which contributes to overall deterioration. Adverse genetic information can come more to the fore and oxidative stress (see below) has a more noticeable effect. The result is the visible *(neuro) anatomical* aging phenomena.

As age progresses, brain volume shrinks, while that of the ventricles increases. The aging processes occur more often in the frontal brain than in the occipital region The prefrontal cortex, the

hippocampus⁹ and the cortex around the hippocampus prove to be the most strongly subject to aging processes. The parietal and occipital lobes are much less sensitive to aging (Kensinger manuscript) (see fig. 7.1.). The biographical and the working memory especially suffer from aging.

Later in life, damage occurs to the DNA as a result of **oxidative stress** (see 8.4.). Oxidative stress occurs when metabolic processes are strained, for instance, by eating too much within a given meal. It decreases when eating smaller amounts of healthy food. For people with moderately stressful diets, the use of nutritional supplements such as resveratrol, green tea, vitamins C and E, fish oil, and tomatoes may help (Pellis et al 2012).

Genetic factors contribute 50% to the cognitive decline aspect of aging. Intelligence is largely genetically determined. High intelligence in childhood gives more cognitive 'reserve' and can compensate for intellectual deterioration. Lower intelligence later in life is often associated with the risk of (chronic) physical disease and therefore with an increased risk of dementia (Deary et al 2009). The late-onset visual and auditory decline also have adverse effects on cognitive performance.

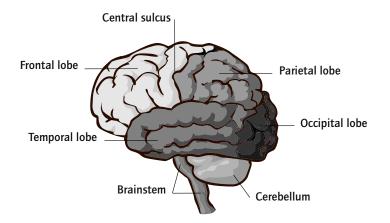


Figure 7.1. Overview of the major brain areas

⁹ a center with an important role for memory storage

7.5. Normal Aging from the Perspective of (Neuro) Physiology

Metabolic processes in the body are subject to a *homeostatic* principle. In health, the balance between synthesis and degradation fluctuates within narrow limits, which become slimmer with aging. Health is in danger, when these limits are crossed. One example of this is the concept of **frailty** in the elderly (Ferrucci 2009). Failing homeostatic principles cause dysfunction of some brain circuits as well as deteriorating connections between these circuits. The homeostatic balance can no longer be maintained. This is visible in emaciation due to loss of muscle tissue, in walking difficulties, balance problems, reduced mobility in people with frailty. Frailty is a predictor of imminent death or severe disabilities within a year (Ferrucci 2009). Less exercise also leads to impaired cognitive function. Conversely, moderately intensive daily exercise improves cognitive abilities (Scherder 2011).

7.5.1. Neuro-Physiological Changes in Normal Aging

In old age, this overall decrease of **physical health** effects cognitive functioning. Hormonal function changes after the fiftieth year, a change that also is reflected in the nervous system. Reduction of estrogen or testosterone levels may ensue in decreased memory function. A reduction in growth hormone production hinders the growth of neurons and their axons¹⁰ and thereby, the recovery of the brain after injury, which causes further memory function decline. The function of neuronal circuits becomes more limited and neuroplasticity¹¹ reduces (Aleman 2012).

Brain plasticity (see Chapter 13) is also reduced by diminishing production of neurotransmitters such as dopamine, serotonin, and acetylcholine at the expense of psychological functions such as motivation, attention, and interconnected memory processes (see box).

¹⁰ nerve fibers

¹¹ possibility to compensate for any change in the brain

The notion that motivation, attention, and other brain functions **are caused** by neurotransmitters, is too simple a view. However, it seems plausible that mental functions need neurotransmitters to come to consciousness, induce activity, and at times be converted into actions. Fuchs (2008) states that the brain functions as mediator between spirit/mind and body.

The impact of heart failure, arteriosclerosis, and high blood pressure results in less oxygen being available for brain functions. However, neuro-plastic brain properties do make it possible for the elderly to enable areas at the rear of the brain for cognitive tasks that normally take place only at the front of the brain in younger people. The same is true for the possibility of switching hemispheres (see also Chapter 13).

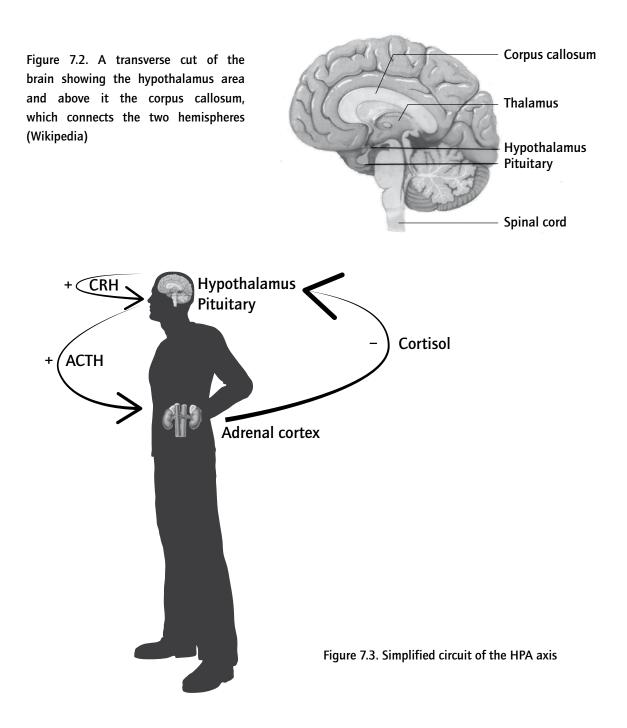
7.6. The Effect of Stress and Inflammation on Normal Aging

Chronic stress leads to permanent changes in the stress axis, or **HPA axis**¹² (see also 11.1.1.). The chain of reactions in this axis is initiated by the hypothalamus (fig. 7.2. and 7.3.). In response to a stressor, the hypothalamus produces the hormone/neurotransmitter CRH¹³, which prompts the anterior lobe of the pituitary to produce the hormone ACTH¹⁴. ACTH will signal to the adrenal cortex to produce the stress hormone, cortisol (fig. 7.3.).

¹² hypothalamic-pituitary-adrenal axis

¹³ corticotropin-releasing hormone

¹⁴ adrenocorticotropic hormone



Cortisol has multiple effects that contribute to one's ability to deal with long-term stress. Cortisol promotes or inhibits the hypothalamus, depending on its concentration in the serum.

The HPA axis may become dysregulated by chronic stress. This abnormal hormone situation creates a new *allostatic* equilibrium. Consequentially, the HPA axis is reset permanently at a higher level. The extra toll, the *allostatic load* (Sterling et al 1988), affects general health and can be damaging. Prolonged elevated cortisol levels as a result of chronic stress indicates an increased risk of developing dementia (Johansson et al 2010).

Cortisol also inhibits the immune system. Deterioration of immune defense makes chronic inflammatory reactions more likely, such as chronic urinary tract infections. These in turn result in an increased risk of inflammatory activity in the brain. The immune system communicates with the brain through cytokines¹⁵ released during inflammatory reactions. Inflammation causes 'sickness behavior.' This manifests in inertia, lack of initiative, depression, anxiety, loss of appetite, and deterioration of cognitive function (Holmes et al 2011). Damage caused by a chronically high cortisol and inflammatory reactions produces in particular neuropsychological symptoms (see box, 'Connections Between Brain Function and Mental Processes', 7.5.1.).

7.6.1. Neuropsychological Changes in Normal Aging

Capabilities such as the vocabulary, counting, and overall development—also called the 'crystallized memory'—remain intact until late in life. The biographical memory as well as executive functions such as those required to prepare a meal, the speed of thought, and the precision of reasoning—the 'liquid memory'—decrease from middle age onwards.

Remarkably, the *emotional memory* does not deteriorate in old age. Older people are even more sensitive to the effects of positive emotions (Gutchess et al 2007).

Because all brain processes are linked to each other, changes in one system affect the other systems. Deterioration of the speed of thought from middle age on is a result of this interlinking and offers an important explanation for the cognitive decline in this period (Deary et al 2009).

¹⁵ messenger molecules

7.7. Conclusion

Each of the four above-mentioned perspectives—life story, (neuro)anatomical, (neuro)physiology, and (neuro)psychology—exhibits aspects of normal aging. At the same time, each perspective harbors possibilities of recovery. Cognitive health during the aging process can be seen as a balancing act. An active attitude towards becoming older reduces the risk of accelerated mental aging. The role of early life stages is remarkable in that these seem to have a major influence on the ability to age in good health (11.2.4.).

The interview with Mr. M illustrates that many of the facets that play a role in this balancing act are signaled by healthy elderly people in the practice of everyday life. We will see that healthy aging has many features in common with the process of dementia. In the next few chapters this will be further elaborated.

Classification, Prevention, and Treatment of Dementia by Marko van Gerven

8.

Alzheimer's disease does not exist. The health care system, biomedical science, and the pharmaceutical industry have been on the wrong track for years. Alzheimer's disease is not a separate entity, and often does not lead to dementia. These stakeholders cling to an outdated and dogmatic understanding of disease.

Olde Rikkert et al (2012)

There are several reasons for this shocking statement. One is that people with Alzheimer's have the same symptoms as others have with normal cognitive aging. In Alzheimer's disease, the same phenomena occur earlier, sometimes even before age 65 and/or in a more severe form, and/ or in conjunction with other disease, such as atherosclerosis or Parkinson's disease. Alzheimer's is not a disease in the ordinary sense of the word, but a syndrome based on compiled symptoms that indicate an accelerated aging process. There is no clear pathological substrate, the cause is unknown and there is no cure for the 'disease.' The prognosis can only be indicated in general terms: an irreversible process with mental and physical decline, which displays a faster than normal physical and cognitive aging process. It is better to talk about various dementia syndromes. This is what we know about the course and demography of dementia:

- In the next few years, a sharp increase is expected in the number of people with dementia in the Netherlands. In 2020, the prognosis is 230,000 and in 2050, the prognosis is 400,000 demented persons. In 2050, a tripling is expected of dementia cases from all over the world compared to the current number of patients. Especially in low- and middleincome countries (in Africa and Asia), the number of people with dementia will rise sharply (Alzheimer's Disease International, 2013).
- Dementia is a progressive disease that shortens life expectancy. No cure is known at this time.

- People often die from complications of dementia, such as fractures or pneumonia complications.
- Only 14% of patients diagnosed with dementia die in the final(fourth) phase.

In this chapter the possible classification of dementia and currently known causes are discussed. Existing treatment is described.

And first, a brief description of the interesting history of Alzheimer's disease is given.

8.1. A Brief History of Alzheimer's Syndrome

In 1907, doctor Aloysius Alzheimer (1864-1915) described the clinical picture and the results of brain autopsy of Auguste Deter, who, in 1902 at 52 years old, was admitted to his psychiatric ward in Frankfurt, Germany. Based on her confusion, anxiety, suspiciousness, insomnia, and severe memory dysfunction—not recognizing her own husband—Alzheimer's initial diagnosis was cerebral palsy. Five years after her death, he was able to perform autopsy on her brain. Large parts of the cerebral cortex were found to be shrunken. In addition, he found microscopic changes: new, strange tangles and plaques consisting of protein deposits. This was a disease not described before. After several more patients with the same symptoms and microscopic findings, Alzheimer named the disease 'senile psychosis, an atypical form of senile dementia' (Draaisma 2006).

Currently, more than fifty different types of dementia are known. Only rarely is a dementia type curable. Of the patients who visit memory clinics, 1% have a reversible type of dementia (Dautzenberg 2013). Much research later, an effective therapy has still not been found. Only preventive measures are described that could possibly prevent half the known cases of dementia.

8.2. Classification of Dementia

In describing the various ways in which dementia is classified, we will limit ourselves to looking at the four most common types of dementia.

8.2.1. Classification Based on Primary and Secondary Forms of Dementia

Primary dementia includes those forms of dementia involving precipitates of insoluble brain proteins. The cause of the pathological precipitation is unknown, but it leads to reduced brain function. Examples are the most common form of dementia, Alzheimer's disease (AD), which accounts for 60% to 70% of cases of dementia, vascular dementia (VD), fronto-temporal dementia (FTD), and Lewy body dementia (LBD).

In **secondary dementia**, a physical illness such as generalized vascular disease or alcohol intoxication, leads to deterioration of cognitive function. Other examples of generalized disease causing dementia are HIV infection, eating meat contaminated with prions (mad cow disease), other poisoning syndromes, diabetes mellitus, hypertension, and depression.

The idea behind this classification is that primary forms of dementia would be irreversible while in secondary dementia the decline could slowed and reversal may seem possible. However, even after treatment of the underlying disease, often no improvement is seen. Patients occasionally remain at the cognitive level of the time the disorder was discovered; they rarely return to their original functional level. Typically, however, the dementia process continues (Lovestone 2009). The abnormalities in the brain appear identical to those in the healthy elderly (see 7.3.-7.6.).

8.2.2. Classification Based on Microscopic Cerebral Changes

Depositions of *tau proteins*, which cause the formation of neurofibrillary tangles inside neuron bodies, are found in AD. Tau protein is normally present in the axons. They stabilize the microtubules in the cytoplasm that form the cytoskeleton. In AD, an excess of insoluble tau protein leads to the disintegration of the neuron. Other forms of dementia like FTD also exhibit neurofibrillary tangles. These tangles are also seen as a normal aging phenomenon in at least one third of the brains of elderly without dementia symptoms (see also 7.3.-7.6.).

Another form of protein precipitation, *alpha-synuclein* precipitate, can be found in LBD, Parkinson's disease (PD), and again in normal aging. Plaques consisting of *amyloid* between neurons occur in

AD, prion diseases, and about one-third of 'normal' elderly.

Problematic in this classification format is the simultaneous presence of multiple protein abnormalities as well as the fact that different forms of dementia may have the same protein abnormalities. Moreover, healthy elderly reveal the same brain changes, apparently without clinical significance (Snowdon 2003). From a clinical perspective, the location of brain tissue loss is more important than the nature of the protein precipitates or the classification as primary or secondary form of dementia (Lovestone 2009).

8.2.3. Distinction of Dementia Types Based on the Clinical Picture

AD and VD usually start with memory deficits. In VD, it often begins suddenly and is immediately accompanied by disorders of movement and speech. FTD typically starts with a decline of social abilities and behavior as well as personality changes. PD often initially reveals an attention deficit, a problem executing intended actions, and a striking decline of language faculties. LBD often begins with attention disorder and the correct assessment of spatial relationships, psychotic symptoms without fear, and changes of locomotion through increased stiffness and inertia. The location in the brain with the most degradation phenomena determines the clinical picture in these dementia types. The problem with this classification format is the large overlap of symptoms between the different forms of dementia.

8.2.4. Classification of Dementia Based on the Course in Time (Phasing)

Dementia progress is usually staged based on the progression of AD, the most common form of dementia, into three or four phases. Lovestone (2009) distinguishes three phases:

- a first phase of two to three years characterized by *memory problems* and *difficulty performing everyday activities*;
- a second phase, in which the *deterioration of the personality and intellect* is fast and symptoms appear related to damage in certain brain areas. Examples include aphasia¹⁶,

¹⁶ partial or total loss of the ability to articulate ideas or comprehend spoken or written language

apraxia¹⁷, agnosia¹⁸, and acalculia¹⁹;

• The third phase is characterized by apathy. The patient is bedridden and doubly incontinent.

Feil (2010) and Verdult (2003) speak of four phases, adding a phase of repetitive psychomotor movements between the second and third stages of the above classification (see also the introduction to Part I):

- the cognitive phase, also referred to as a disorder in spatial orientation (malorientation). Verdult calls this is the phase of the 'endangered' I;
- the emotional phase, including a disorder in time orientation (time confusion); Verdult's term is the phase of the I 'astray;'
- the psychomotor phase with repetitive movements; Verdult calls it the 'hidden' I;
- the sensory (vegetative) phase; corresponds to Verdult's phase of the 'receded' I.

Phases mentioned above can sometimes follow each other in short succession. The disease course of increasing decline is irreversible.

The division into four phases seems very manageable in daily practice and provides a good starting point for targeted therapy. We see this classification format as the most fruitful method in daily practice.

8.3. The Diagnosis of Dementia

In clinical practice, dementia is generally diagnosed on the basis of clinical signs (Directive NVKG 2005). A study of 209 elderly people who had autopsy on their brains performed after death revealed that vascular abnormalities (78%) and Alzheimer symptoms (70%) are a regular occurrence. The diagnosis of dementia was made in only 48% of the total group. The non-demented group of deceased, however, also had rich microscopic pathology including Alzheimer's plaques (33%) and neurofibrillary tangles (34%). The vascular abnormalities in the brain were present in both groups: 46% in the group with dementia compared to 33% in those who had no clinical dementia (MRC CFAS 2001).

¹⁷ inability to carry out actions in a correct manner

¹⁸ Impairment in the ability to process sensory information

¹⁹ difficulty performing simple mathematical tasks

These figures further indicate on the one hand the small extent to which pathological processes found in the brain point with certain to one form of dementia or another. On the other hand, there is a group of elderly people who did not have dementia, but does have significant pathological aging in the brain (see 7.4., 8.2.2., and 14.6.). There appears to be no reliable 'test' to diagnose dementia so far. The *probable diagnosis* of dementia can only be made on the basis of clinical symptoms.

The fact that brain aging processes can be completely unrelated to mental function raises the question of the relationship between the two.

8.4. Break-Down and Repair Processes

A recent experiment (Vogel-Cierna 2013) involving 'Alzheimer mice,' which were selected genetically for an abundance of amyloid and tau protein in the brain, showed that repair after (double) breaks in the DNA of these mice is much less effective than in healthy mice. In the healthy group of mice, the breaks were repaired within one hour after exposure to a new environment. This is an example of the incredible plasticity in the brain (see also Chapter 13).

Neuroplasticity is the counterpart of aging. Why and how does the brain age?

In Chapter 7, we discussed a long-standing theory that '*free radicals*' promoting oxidative processes are a major contributor to aging (7.4.). Oxidative reactions break down tissue and are held responsible for (accelerated) cell aging (Harman 1981).

Lipofuscin is specifically related to neuronal aging (Swaab 1991). The effect is blocked by antioxidants. The hypothalamic neurons that do not contain lipofuscin naturally are particularly susceptible to breakdown by aging. The aging process can cause inactivity in all body systems, which leads to negative chain reactions. Conversely, there is evidence that a higher the level of physical or mental activity is associated with a lower AD risk (Rovio et al 2005).

8.5. "Use It or Lose It:" Preventive and Remedial Measures in Aging and Dementia

Both in normal aging and in AD, we find brain atrophy. At the same time in healthy elderly as well as in elderly with dementia, neuronal repair processes can be detected owing to brain plasticity

(Swaab et al 1998). A 'rich' environment provides neural stimulation and increased repair ability to counter breakdown processes in neurodegenerative disorders. This can be promoted with several measures:

- By creating a 'reserve.' Exposure to a childhood environment rich in impressions leads to a passive 'reserve.' Later in life, being mentally active and ensuring good quality interactions with the environment can create an active reserve. In the latter case, permanent mental or physical activity ('use') is required to prevent loss of capacity ('lose'). These measure are most effective at the beginning of the dementia process (Scherder 2011);
- By encouraging *behavioral change* in the form of increased physical activity, a no-smoking regimen, and treatment of existing hypertension. According to Scarmeas et al (2009), at least 50% of future Alzheimer's patients may delay or prevent the disease this way;
- Feil (2010) uses staging to introduce *phase-specific interventions*. She states that patients do not have to come in the last vegetative phase of dementia when they are correctly attended to in earlier stages;
- By preventing the formation of free radicals. Prevention of obesity from childhood on is an important measure to achieve this. A protective effect against the formation of free radicals has been described in connection to the use of vitamin E and C The Mediterranean diet is beneficial in diseases such as atherosclerosis and hypertension owing to its capacity to reduce oxidative processes.

The following measures to treat or prevent dementia are still more or less theoretical and have not yet been tested by reliable and effective methods:

- boosting the intake of foods and factors that promote the development of neurons;
- providing specific *hormones*;
- the administration of neurotransmitters (Swaab 1991; Black et al 1991);
- the use of *medication* to treat dementia. These may slow the progression of the dementia for a period of six to nine months (Eikelenboom et al 2010).

8.6. Conclusion

This brief overview illuminates the importance of a balance between pathological and repair processes in different physical systems to the onset of dementia. There are large individual differences in how the onset of dementia transpires and in its course. The next chapter will delve deeper into the profile of dementia in order to gain more insight into individual differences. From the information presented here, it is clear that the observed macro and micro neuro-anatomical changes not determine the clinical picture of dementia. The principle "use it or lose it" is by far the most important factor found in the prevention of dementia. Both mental and physical activity are essential. More than half of potential Alzheimer's patients could possibly delay or prevent illness through behavioral change such as more exercise and better diet (Scarmeas et al 2009), coupled with smoking cessation and hypertensive therapy if needed. This finding suggests that dementia may be associated with the activity and the developmental prospects of the I or self of the (potential) patient. In practice, the potential and prospect of the I is likewise perceived as essential: different phases of dementia are described as deviations in the perception of the self (see Introduction to Part I and Part III).

9. Diagnosing Dementia by Marko van Gerven

9.1. Introduction

This chapter investigates various diagnostic methods for dementia. In Chapter 8 we discussed how diagnosing dementia is best done on the basis of observed clinical symptoms. These are described below for the four most common types of dementia. How dementia manifests itself is chiefly determined by where and how the destructive processes occur in the brain. Further testing allows greater diagnostic certainty, however, there is more than one reason to be cautious about making a diagnosis and establishing a definitive prognosis:

- As was first discussed in Chapter 8, repair processes may favorably affect the course of (new onset) dementia.
- Upon autopsy, roughly a third of people had more or less robust dementia symptoms in their brain, but no clinical evidence of dementia. This means that the diagnosis of dementia cannot be confirmed on the basis of pathology alone.
- Moreover, the same symptoms can be associated with different types of dementia.

It is therefore practically impossible to provide diagnostic and prognostic certainty in individual cases. The recently released DSM-5 (APA 2013) speaks instead of mild or severe neurocognitive impairment (see box).

Diagnostic Criteria of (Minor and) Major Neurocognitive Disorders According to the DSM-5

- There is evidence of (modest or) substantial cognitive decline from a previous level of performance in one or more of the domains outlined above (complex attention, executive functions²⁰, learning and memory, language, motor and social abilities) based on:
 - 1. the concerns of the individual, a knowledgeable informant, or the clinician;
 - 2.and a decline in neurocognitive performance, typically involving test performance in the range of (one or two) two or more standard deviations below appropriate norms (i.e., below the third percentile) on formal testing or equivalent clinical evaluation.
- The cognitive deficits are sufficient to interfere with independence (i.e., requiring minimal assistance with instrumental activities of daily living).
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits are not primarily attributable to another mental disorder (e.g., major depressive disorder, schizophrenia)

Having determined whether a patient has a major or minor neurocognitive disorder, the healthcare professional making the (probable) diagnosis must then decide on the etiological subtype of the major or minor neurocognitive disorder. The subtypes that have been listed are neurocognitive disorder due to AD; VD; FTD; neurocognitive disorder due to traumatic brain injury, LBD, PD, or HIV infection; substance-induced neurocognitive disorder, etc.

Except for determining whether the cognitive disorder is minor or major, the diagnosis must also be specified with the degree of diagnostic certainty: *suspected* or *probable* and an indication of whether or not there is a mood disorder, psychotic symptoms, or behavioral problems such as agitation or apathy. Finally, the degree of severity at the time investigation is mentioned: mild, moderate, or severe.

²⁰ having the power to put plans and actions into effect

9.2. Clinical Criteria for the Four Most Common Types of Dementia

The following descriptions are written, in particular, on the basis of the research of Lovestone (2009).

9.2.1. Clinical Criteria for Alzheimer's Disease (AD)

Impaired memory, problematic language expression, and planning problems come early in AD. The loss is initially limited to memories of events of the last few years. The work-memory, which enables recall of several concepts simultaneously, is intact. But asked a few minutes later about what one was doing beforehand, the patient seems unable to save and retrieve recent activities from the memory bank. To be more specific, the memory problem in AD seems to be slightly more related to the capacity to 'save' memories than to the ability to retrieve previously stored memories, but when AD progresses, past memories are also lost. Amnesia in AD involves the episodic memory²¹, the semantic memory²², and visual-spatial abilities, leaving the recognition of a familiar environment difficult. The memory seems to 'curl up' and the here and now becomes inaccessible. The curling up of memory also implies that previous life events may be remembered with all vehemence. This can initiate behavioral problems.

The following neurological symptoms are often present:

Aphasia: Loss of the ability to understand spoken language or to use the right words at the right time. This is a major barrier to effective communication

Apraxia: problems in the implementation of complex motor movements. This problem leads to dependence on others in self-care and also to conceivable misjudgment in avoiding dangers, for example when using kitchen appliances

Agnosia: inability, for example, to recognize oneself in the mirror or to recognize the well-known other

Executive functions such as the ability to plan, organize, and keep attention to what one is doing

²¹ the part of the memory where personal memories, events are stored

²² memory with regards to factual knowledge and language ability

are lost relatively early in AD. It is believed that this feature is associated with dysfunction of the frontal cortex (cortical symptom).

Other symptoms like hyperorality²³ or hyperphagia²⁴ indicate deficiencies in the temporal cortex area. Eventually the ability to carry out the ADL²⁵ becomes much reduced. Again there is no direct relationship between the deterioration of the ADL and cognitive loss (Teri et al 1989). Rather, there is a correlation between increasing age and deterioration of carrying out the ADL.

Behavioral and psychological symptoms are common and exist not a result of the dementia process, but rather as a part of it. Common symptoms are **anxiety**, **depression**, **agitation**, **problems with diurnal rhythm (sleep disorders)**, **apathy**, and **psychotic symptoms**. These are the symptoms that have the greatest impact on care givers (Coen et al 1997; Donaldson et al 1998) and that often lead to admission to a nursing home.

Psychotic symptoms like hallucinations²⁶ and delusions²⁷ (Hengeveld 2005) are associated with inner tension and anxiety and lead to behavior problems such as contrariness and aggression. The most common delusion is that of personal item theft. Hallucinations are more frequently visual than auditory. Sometimes, psychotic symptoms may play out as a re-experiencing of major traumatic events in a patient's history.

Mood symptoms like depression may be an early symptom of AD, can include pre-AD symptoms, and can lead to an incorrect diagnosis (pseudo-dementia) (Lovestone 2009). Depression is often under-treated in the elderly even though response to treatment in old age is as positive as in youth.

Progression Over Time

AD is an example of a neurodegenerative disorder with an insidious onset and progressive worsening over time, which makes the timing difficult. The duration of the declining course can vary greatly with an average variance of about ten years. AD is rare before the sixtieth year.

²³ tendency to put objects into the mouth

²⁴ eating things that are not meant to be eaten

²⁵ Activities of Daily Living

²⁶ experiencing sensory perceptions, when there is no outer sensory stimulus

²⁷ disorders in the content of thought, consisting of personal and fundamental beliefs that are contrary to reality and that persist, despite conclusive evidence to contradict them

Genetic Changes

An AD-causing genetic mutation (polymorphism, apolipoprotein E4, trisomy 21–Down syndrome–, and rarer mutations) may be present in the family of origin or are found in genetic enquiry. When a genetic mutation is present, AD manifests itself earlier in life.

9.2.2. Clinical Criteria for Vascular Dementia (VD)

VD likely to be present with other forms of neurocognitive disorder, especially in combination with AD. There are also quite a few older people, who have VD and AD brain pathology and no signs of dementia. VD is divided into four types:

- Multi-infarct dementia: arteriosclerosis of the peripheral brain vessels is often associated with hypertension. Since the lesions are disseminated throughout the brain, the presenting symptoms are hard to predict. However, onset is often more abrupt (specifically when there is a stroke²⁸) compared to other forms of dementia. When the course is more gradual, emotional or personality changes are more common than memory problems. In addition, thinking is delayed and planning activities become problematic. Often, prolonged physical symptoms like headache, dizziness, tinnitus, and palpitations are present. The severity of symptoms that may occur include hemiparesis²⁹, altered sensory experiences, and aphasia. The memory decline also happens incrementally. Eventually, a pseudobulbar palsy may appear, which is a combination of symptoms of dysarthria³⁰, dysphagia³¹, and emotional lability. Also, the way the patient moves may change with symptoms like bradykinesia³². Many patients are aware of their cognitive decline, which can lead to anxiety and depressive symptoms;
- Dementia due to abnormalities of the small blood vessels: these abnormalities often result

²⁸ cerebrovascular accident or stroke

²⁹ hemiplegia

³⁰ problems with articulation

³¹ swallowing disorder

³² slowed down movements and reduced size of steps while walking

in loss of white matter, but cavities can also occur in the cerebral cortex. These alterations are primarily related to age and are some of the sequelae of pre-existing hypertension. These also lead to memory problems. Loss of white matter³³ in the vicinity of the ventricles, basal ganglia, and the thalamus is specifically accompanied by **a delay in thinking** and dementia. The clinical picture is not observably different from the multi-infarct dementia;

- *Dementia after experiencing a stroke*: People over 55 who have experienced a stroke have an increased risk of dementia. More than 30% develop a neurocognitive disorder in the five years after the stroke compared to 5% in the general population (Leys et al 2005);
- *Specific vascular syndromes leading to dementia*: some rare familial syndromes are accompanied by dementia. These people often suffer from **migraine**, repeated **subcortical infarction**, **transient ischemic attacks**, and **severe mood disorder**. This type of dementia can have its onset when people are in their forties.

9.2.3. Clinical Criteria for Lewy Body Dementia

Lewy bodies are found as neuronal inclusions in PD, but they can also be found disseminated in the brain independently from that in neurocognitive disorders. Clinical symptoms include:

- **fluctuating symptoms of confusion**: the picture may change from hour to hour or day to day. Acute confusion, often leading to hospital admission, may suddenly disappear again. These fluctuations are more pronounced than in other forms of dementia. The underlying cause is perhaps based in the fluctuations of consciousness, which are much more pronounced in LBD than in AD. However, a clinically significant cause for these variations has not been found. The picture may resemble that of a delirium. In PD only, strong variations in the capacity to focus the attention occur.
- **visual hallucinations**: it is striking that hallucinations are usually silent and cause little to no fear. They appear more frequently than in AD. When psychotic symptoms occur in early

^{33 (}inner)part of the brain with mostly nerve fibers

dementia, LBD must be considered as a possible diagnosis. Other psychotic symptoms that occur are **hallucinations of other sense organs**, **delusions**, and **depression**. When **extrapyramidal symptoms**³⁴ occur along with these, the diagnosis LBD can be strongly suspected. Because these patients tend to have extrapyramidal symptoms, the usual antipsychotics are contraindicated (see also patient A, Chapter 1);

- **Parkinsonism**: this phenomenon is part of the diagnosis LBD if it occurs within a year after the onset of dementia. Rigidity and movement problems are core symptoms in particular, while an ongoing tremor may be less conspicuous. In the initial phase of LBD, memory problems are less pronounced than in Alzheimer's. Depressive disorders are more frequent than in AD. Patients with LBD die relatively early (within 1.8 years after diagnosis) as compared to 4.8 years for patients with AD (McKeith et al 1992);
- progressively worsening cognitive problems;
- additional features: increased **tendency to fall**, **palpitations**, **delusions** (McKeith et al 2005);
- **REM sleep disorder**. This disorder consists of repeated nocturnal arousal combined with eruptive and/or spontaneous calling out and/or motor behavior patterns. During these REM sleep periods the patient is asleep and is not conscious of their eruptive behavior. Symptoms manifest particularly in the second part of the night. When patients do wake up, they are well oriented and not confused. This symptom may occur early in the course of the disorder;
- Syncope and temporary episodes of loss of consciousness, without apparent cause.

³⁴ muscle twitching of the face and tongue, convulsive and painful stretching of large muscles, trembling hands, and face mask

9.2.4. Clinical Criteria for Fronto-Temporal Dementia (FTD)

The term FTD is used for dementia in which the front part of the brain degenerates. It is characterized by behavioral and personality changes and is more common between the ages of 45-65 years. FTD has two variants:

- The form in which **behavioral disorders** are first perceived: disinhibition, stereotypies³⁵, compulsion, impulse control problems, and antisocial behavior. Memory may still be mostly intact. Other behavioral problems are apathy or inertia, loss of empathy or inadequate expression of appreciation, hoarding, and hyperorality. A decline of social abilities and executive functions may also be present;
- The **language variant form**: a semantic dementia exists, which consists of a combination of the loss of memory for words, prosopragnosia³⁶, and memory problems, especially for events in the past. There may also be a non-flowing form of progressive aphasia, meaning a combination of the loss of the flow element in speech, a word finding difficulty, and loss of grammatical knowledge.

The progression in time of FTD is characterized by its early appearance in life (before the sixtieth year). After diagnosis, the survival time is three to four years.

Genetic factors play a role as 40% of patients with FTD have a positive family history for early onset dementia and 10% of patients have an autosomal dominant pattern of inheritance for the disease.

9.3. The Added Value of Additional Testing

Added tests play a role in distinguishing between primary and secondary forms of dementia (8.2.1.). In AD, cerebral atrophy, amyloid plaques, and neurofibrillary tau-protein tangles can be established, the latter two histopathological findings only after death by **autopsy**. In early onset AD, mutations can be determined of amyloid precursor protein (**APP**), and **presenilin 1 and 2** (PSEN 1 and 2). PSEN2-determination is available as a commercially available test. Apolipoprotein **E4** is not a

³⁵ movements/actions that are repeated, manifest aimlessly

³⁶ loss of the ability to recognize faces of others/self

diagnostic marker, but rather a risk factor (10.1.1.).

Primary dementia generally reveals no specific diagnostic abnormalities in blood, urine, or cerebrospinal fluid, nor can these be found with current imaging techniques (Lovestone 2009). However, EEG studies may aid in distinguishing between AD (early nonspecific abnormalities) and FTD (no early abnormalities). Imaging techniques do not show sufficient characteristic difference between various dementia syndromes.

Diagnostic efforts are important in the context of secondary dementia because treatment of vitamin B_{12} deficiency, hypothyroidism, normal pressure hydrocephalus, or brain tumors, for example, can sometimes lead to a degree of recovery of the dementia process. Testing is also important to exclude more rare secondary dementia syndromes. However, the result of therapy is often discouraging (8.3.).

9.4. Conclusion

The discussed clinical syndromes differ from each other, especially at the onset of the dementia process. Strikingly, the course over time is perhaps the most characteristic symptom for the discussed forms of dementia. The acute onset and stepwise process of VD, the strong fluctuations in consciousness and fast course of LBD are typical properties of these disorders. AD distinguishes itself from other forms of dementia on the basis of a slowly deteriorating course and by localization, since patients have symptoms of a cortical form of dementia³⁷ (Lemstra et al 2004). The other form of cortical dementia, FTD, has a gradually progressive course over three to four years before the age of sixty with core symptoms of behavior and language disorders. In it this form, memory deficiencies occur at later stages.

Subcortical symptom complexes are not mentioned in either the DSM-IV-TR or DSM-5 criteria for dementia/neurocognitive disorder (APA 1994; 2013). They mainly consist of inertia and reduced flexibility as well as apathy, attention disorders, disorders in problem solving and trouble retrieving current information. Patients are generally slow and ineffective, and exhibit disturbed affect (Lemstra et al 2004). LBD and VD symptoms are both subcortical and cortical in nature. AD and

³⁷ memory disorders with disorders of language and executive and cognitive functions

FTD have many neuropsychiatric symptoms in common, which are also subcortical in nature. If one adds to this the circumstance that different forms of dementia sometimes co-exist in the same person at the same time, one realizes that the diagnostic distinction of different types of dementia based on clinical criteria and localization in the brain is of relative value. On the other hand, diagnosing a secondary form of dementia rarely leads to an actual remission of the symptoms (Lovestone 2009).

The combination of a descriptive diagnosis and added testing leads to a sensitivity of the diagnosis of dementia of 88% (Burns et al 1990).

In practice, the probable diagnosis of neurocognitive disorder is made chiefly based on clinical characteristics and behavior of the patient (Verheij 2013).

10.Risk Factors for Dementiaby Marko van Gerven

The investigation of diagnostic criteria in Chapter 9 led us to the conclusion that existing clinical criteria are of limited value for assessing individual patients' features in relation to different forms of the dementia process. Can a clustering of risk factors contribute to a perspective of neurocognitive decline that allows an individualized diagnosis and prognosis for the course of dementia?

There are quite a few well-known risk factors for dementia. Without regard to aging, any other individual risk factor only contributes in a minor way to the onset of dementia. By clustering risk factors, however, diagnostic patterns have become clear, which have proved helpful in understanding the clinical signs of neurocognitive disorder. These patterns or risk factor subgroups have the potential to clarify the profile of dementia onset and the course of the disease. In a previous publication (van Gerven & van Tellingen 2010) we followed up on the approach of the psychiatrist McHugh (1998) and developed four subclasses of risk factors for mood disorders that each represent a different biological system. We used the same subdivision for the risk factors pertaining to neurocognitive disorders.

Cluster 1. Neuroanatomical processes of brain structures.

Deviations at this level are directly and tangibly observable. In his approach to psychiatric disorders, McHugh calls this cluster the 'disease perspective' in view of the treatment options. It gives indications for *classical medical treatment* (10.1.).

Cluster 2. *Neurophysiological and neurochemical processes* in the brain and elsewhere in the body. This group of disorders is rooted in deep-seated (unconscious) physiologic patterns and specifically asks for a therapeutic approach based on *behavioral interventions* (10.2.).

Cluster 3. The *communication systems* that constitute the physiologic basis of emotional processing. Unresolved emotions often form the basis for adjustments of the stress axis (HPA axis, see 7.6.). Eventually this leads to brain damage. Addictive behavior, for example, can be seen as an attempt at self-healing of unresolved emotional stress, but eventually leads to physical damage. The treatment from this perspective is directed at *guiding learning processes and dedicated to behavior change* (11.1.).

Cluster 4. Effects from external events that *become part of the authentic life story*, partly due to one's own reactions. A *coaching approach and rewriting the script of life* is the primary therapeutic policy from this perspective (11.2.).

"When someone already has dementia, what is the use of all this?" seems a logical objection. Indeed, it is too late to reverse many of the disease processes. However, during the progressive course of dementia, neuroplasticity still holds the potential to alter the course of deterioration, as became clear in Chapters 2-6. This means that even when brain anatomical structures are damaged, their function can be supported such that the individual can be present at important moments. As more symptoms arise, more help from the environment will be necessary. Besides the stimulus from drugs, diet, and physical activity (8.5.), the reduced stress tolerance and the phenomenon of the 'reversal of memory' pertaining to the life story (7.3.) must also be addressed. Some examples of these are described in preceding chapters. Clinicians and caregivers are greatly aided by awareness of the important milestones in the life of the individuals concerned for the purpose of understanding and supporting their behavior.

10.1. The 'Disease Perspective' of Dementia: Neuroanatomical Factors

The risk factors for neurocognitive disorder, which can be clustered as neuroanatomical in nature, point to diagnostic signs and symptoms of a process that is stalled in a physical/structural sense. The chronic nature of such disorders is obvious. Dementia can be seen as a chronic process with loss of nerve tissue (atrophy), structural brain abnormalities, and the disappearance of neurotransmitters from the perspective of this cluster. As of now, an effective medical treatment does not exist. However, great gains have been made with stage specific interventions related to the phases of changing I-experience. As stated earlier, this development also occurs in normal aging processes.

10.1.1. Genetic Factors

Dementia, due to *genetic factors*, is associated with premature atrophy of nerve tissue, structural brain abnormalities, and the loss of neurotransmitters. One genetic form of dementia occurs when a change in the **APP gene** causes the production of an abnormal insoluble amyloid beta (A4) protein. A4 is a precursor of amyloid protein, which is found in the brain plaque of people with dementia (see also Section 9.3.). Chronic inflammatory factors are conceivably involved in the abnormal deposition of amyloid in this situation. In early forms of dementia and Down's syndrome, this abnormal accumulation of protein also seems to play an important role.

When dementia occurs later in life, the **APOE gene** is an important contributing factor. The chance of inheriting this form of dementia is 60-70% for those carrying the gene (Lovestone 2009). Those carriers with the APOE-e4 gene in particular have a three-fold increased risk of developing dementia. Nevertheless, individual case testing on this gene does not determine the diagnosis of a neurocognitive disorder nor does it answer the question of whether or not the individual will respond to cholinesterase inhibitors (see 10.1.2.). The genetic abnormality does mean that proteins crystallize earlier and that deviations in protein structure do occur.

10.1.2. Loss of Neurotransmitters

At a physiologic level, there is loss of cholinergic neurons in dementia. The neurotransmitter acetylcholine plays an important role in the memory processes. Acetylcholine deficiency has adverse effects on memory function. Attempts to replenish the deficiency with lecithin have led to the emergence of the cholinesterase inhibitors as a medical intervention for dementia. Research into the effects of the cholinesterase inhibitors found that there is also a considerable loss of dopaminergic and noradrenergic neurons in dementia. In addition, the activity of the neurotransmitter glutamate, which also plays a role in the memory and learning processes, is severely reduced. In turn, this has resulted in the development of the drug memantine, which stimulates the production of glutamate. The effect of these drug interventions is a (temporary) delay of the dementia process (Medicine Net.com; Lovestone 2009).

10.1.3. Epigenetic Factors

Brain proteins can also become crystallized too early due to epigenetic factors like oxidative stress, toxins, radiation, or accelerated arteriosclerosis. When dementia occurs as a result of changes in the **epigenome**, the DNA itself is not altered but DNA expression changes due to a modified folding of proteins under the influence of the various chemical challenges. Misfolded proteins ultimately lead to the death of neurons. This is a major cause of the primary dementia (Maarel van 2008, Lemstra et al 2002).

Functional blockages may also occur when epigenetically active histones are produced in excessively large amounts under the influence of the enzyme histone deacetylase, an example of which is Alzheimer's disease (Graff et al 2012). The histone causes an increase in the production of misfolded proteins, leading to deterioration of neurons. Neuronal death can also increase through (repeated) brain trauma, normal pressure hydrocephalus, tumors, infection of the brain, generalized internal disease, and cerebrovascular accidents.

From the 'disease perspective' of neuroanatomical dysfunction, treatment will often be pharmacological. However, oxidative stress can also be treated with dietary means (Pellis et al, 2012). For a period of five weeks, healthy overweight men were given a dietary supplement consisting of resveratrol (a polyphenol present, for example, in the skin of red grapes), green tea extract, vitamin E, vitamin C, fish oil, and tomatoes. The measured effect, concluded on the basis of metabolic and inflammatory serum levels, was a reduction in oxidative stress and inflammatory activity compared to men who did not get these additives. This is an example of a favorable epigenetic change, whereby, a longer-term change of diet (lifestyle change) can reduce oxidative stress, inflammatory activity, and consequently arteriosclerosis, and dementia. Another example of a beneficial epigenetic effect comes from a 'rich' environment. Mice that were offered a large fully equipped cage and a lot of social interaction with other mice have been shown to have increased formation of new neurons, and an increase in synaptic plasticity. In later life, learning new skills, such as reading or speaking a foreign language, and being socially active, is protective for the brain, according to the principle *"use it or lose it"* (see 8.2.).

10.2. The Neurophysiological and Neurochemical Perspective

10.2.1. Frailty

When the homeostatic balance is disturbed, disease symptoms can occur. A good example of such a process in old age is frailty (see also van Gerven & van Tellingen 2010). Due to lack of homeostasis, coherence between different functional brain circuits cannot be adequately maintained. Co-operation of these circuits is needed for important functions in daily life such as the ability to walk properly. In frailty, problems walking due to reduced muscle mass go along with degenerative changes in the prefrontal cortex. Balance problems can occur as a result of minor bleeding in both the parietal and occipital cortex areas. Moreover, problems arise between the different circuits needed for ambulatory activity (Ferrucci 2009). Essentially, the effects of reduced coordination between the circuits have a much greater effect than the sum of the anomalies of each individual circuit (Brown et al 2000). Frailty, like mild cognitive impairment, is a precursor to dementia and unfavorably affects treatment outcome of psychiatric disorders in the elderly (Oude Voshaar 2013). Gait disorders occur early on in dementia. Positively influencing homeostasis by regular exercise is beneficial for maintaining ADL and thus for maintaining independence (Scherder 2011).

10.2.2. Mild Neurocognitive Impairment

Minor Neurocognitive Disorder (MND, DSM-5, 2013) symptoms are on the same continuum as the symptoms of the more severe form, major neurocognitive disorder. Neurophysiological changes such as a delay of thought processes are present. The symptoms include problems with memory, language, and judgment as people age. Although the changes interfere with normal daily life, they do not lead to the need to give up independence. According to the criteria of the Mayo Clinic, the following symptoms accompany it:

- · forgetting important appointments or social engagements;
- losing the thread during a conversation, when reading a book, or watching a movie;

- needing to put up a lot of effort for making decisions, planning steps to accomplish a task, or understanding instructions;
- having trouble finding the way in a familiar environment;
- increased impulsivity or increase of incorrect judgment;
- having additional symptoms such as depression, irritability, aggression, anxiety, and apathy.

Family and friends are aware of the changes. With imaging techniques and autopsy, similar anatomical abnormalities are found as in Alzheimer's or other dementias.

The main risk factors for MND are: age, the presence of the APOE-e4 gene, and to a lesser extent, diabetes, current smoking, depression, high blood pressure, high cholesterol, lack of exercise, and lack of participation in mentally or socially stimulating activities. Only 7.5% of people with MND (in the general population) actually develop major neurocognitive disorder (Lovestone 2009). The inclusion of this classification in the DSM-5 has been controversial because of the risk of due medicalization. The primary arguments against the diagnosis of MND are substantiated by the proportionally low percentage of people who's MND turns into dementia and the lack of validated drug treatment options. Typical dietary and lifestyle suggestions and advice to patients with MND are: regular exercise, a low-fat diet high in omega-3 fatty acids and rich in fruits and vegetables, intellectual activities, social activities, and memory training techniques. In integrative medicine, vitamin E, ginkgo, and other resources are recommended, however, as of yet there is no scientific evidence as to the effect of these. Naturally, co-treatment of co-morbid conditions such as hypertension and diabetes mellitus are important.

10.2.3. Other Physiologic Risk Factors (Lovestone 2009)

Non-neurological risk factors may occur at all physiologic levels in all organ systems:

- Vascular risk factors include hypertension, smoking, and peripheral arterial disease;
- Elevated levels of homocysteine lead to endothelial damage and is related to heart attacks and AD. It is possible that folic acid has a preventive effect;

- Insulin resistance in type II diabetes mellitus leads to an increased risk of dementia, not just as a result of vascular disease in diabetes. Insulin regulates both APP metabolism and the phosphorylation of tau protein, which is part of the brain tangles. When insulin resistance occurs, both processes influence the increase of pathological lesions (Solano et al 2000; Hong & Lee, 1997);
- Additional estrogen does not prevent the onset of dementia. Despite initial optimism that would have estrogens gifted with neuro-protective properties, hormone replacement therapy could not prevent dementia as several studies have shown (Mulnard et al 2000; Thal et al 2003).

10.3. Conclusion

Clustering two main groups of risk factors for dementia provides clarity about these factors and their possible preventive potential. A southern European diet, the use of supplements (Bailey et al 2013), a healthy, active lifestyle (Pikkälä et al, 2013), and good blood pressure and diabetes control appear to make a significant contribution in the prevention and progression of dementia. Two other groups remain to be discussed in the next chapter.

11. The Stress Axis and Traumatic Life Story Events as Risk Factors for Dementia

by Marko van Gerven

The previous chapter dealt with two clusters of risk factors for dementia: the disease perspective of structural-anatomical factors and the physiological processes (intro Chapter 10). In this chapter, the influence of the other two clusters of risk factors will be discussed. First, the effect of an activated stress or HPA axis on the development of dementia is addressed, then the risk factors associated with events in the individual's life story.

11.1. Psychological Stress as a Risk Factor for Dementia

Research has shown that there is a relationship between chronic stress and dementia (Peavy et al 2012; Qureshi et al 2010; Yaffe et al 2010). A similar relationship is found between depression and dementia (Panza et al 2010). In addition to the altered stress hormone system that is found in dementia, chronic stress, and depression, these conditions also increase inflammatory activity in the brain. Cardiovascular risks are also amplified by the same mechanism.

Modern stress concepts assume that stress produces both a consciously and unconsciously perceived threat to the homeostasis described in Chapter 10, which is present in the healthy state. The stress response is a reflection of the *nature of the homeostatic threat*, the *perception of the stressor*, as well as *response capabilities* (Goldstein & Kopin 2007). The brain supports stress reactions by coordination of behavior, support of planning, and the secretion of neurohormones. These changes occur not only during activity; at rest hormonal processes are altered as well. The active adaptation to changing external conditions is called *allostasis* (Sterling & Eyer 1988). Prolonged changes can lead to changes in behavior and/or altered physical processes, such as hypertension. Allostatic response can be cumbersome in the long run, leading to, for example, chronic sleep disorders or a sustained increase in blood pressure. The long-term effects of stress are described as allostatic load and are a health hazard. This may also manifest itself as an increased risk of dementia.

Finally, it is important to remember that family members and caregivers who care for Alzheimer patients are themselves also exposed to much stress and feelings of helplessness, which can adversely affect their health.

11.1.1. Acute and Chronic Psychological Stress

It is difficult to demonstrate psychological stress. We are dependent on a patient's memories when attempting to recognize allostatic changes in the stress axis or HPA axis (7.6.) when the stress is related to events long ago as seen in Vietnam veterans or in demented elderly people. There is an important physiological difference in the type of response of the HPA axis between recent events and events that occurred much earlier in life. In stress due to recent events, there is usually elevated cortisol secretion by the adrenal cortex, especially in the early morning, while chronic stress cortisol levels in the blood are often *reduced*. These changes have different effects on different people, some showing aggressive behavior, while others retreat.

A Finnish study reported a 65% greater chance of getting dementia in women who experienced constant stress in middle age. In the study, 1,462 women between the ages of 38-60 years old were observed for 35 years. They completed a stress questionnaire every five years and were clinically assessed for dementia. Women who reported constant stress on one, two, or three study dates, were found significantly more likely to develop dementia (Johansson et al 2010). This finding is supported by a special investigation of people who were examined psychologically 28 years before the outbreak of dementia. People with sensitivity to stress, anxiety, and depression have an increased risk of dementia (Terracciano 2013). Conversely, people with 'resilience' (see 11.2.) have a lower risk of dementia.

11.1.2. Stress Hormones and Inflammatory Processes as Harbingers of Dementia

The stress hormone **adrenaline or epinephrine** is produced by the adrenal medulla in acute global threats. Adrenaline facilitates primarily passive reactions such as the freeze reaction. Norepinephrine, produced in the medulla oblongata³⁸, facilitates active reactions, such as flight, fight, or defusing

³⁸ part of the hindbrain, continuous with the spinal cord, responsible for the control of respiration, circulation, and other autonomic bodily functions

danger actively (i.e. coming up with a diversion, etc.). The stress hormone cortisol, from the adrenal cortex depending on whether its serum level is low or increased, either stimulates or inhibits the central nervous system, especially hypothalamus and pituitary, in secreting adrenocorticotropic hormone (ACTH). This circuit between the brain and the adrenal cortex is called the stress axis or HPA axis (7.6.). Activation of the adrenal medulla and the HPA axis may happen at the same time. Adrenaline and cortisol in particular can cause allostatic damage in the long term. Allostatic stress damage also occurs in insulin resistant diabetes, metabolic syndrome, heart failure, and when inflammatory brain reactions are activated. They also lead to the experience of psychological stress (distress), anxiety, and depression.

Depression can lead to a decreased production of **BDNF**³⁹, thereby diminishing neuroplasticity (Chapter 13). Cure of the depression by means of antidepressants or psychotherapy sometimes leads to recovery of the BDNF and then ensures the formation of new neurons. Chronic depression is accompanied by atrophy of the hippocampus and prefrontal cortex (Karatsoreos & Mc Ewen 2011). It is therefore important to treat depression in older people with dementia. Depression may also be the first sign of dementia. Experiencing depression earlier in life or in old age doubles the risk of dementia. All factors mentioned in above paragraphs may either individually or in combination play a role in different dementia syndromes (Byers & Yaffe 2011).

Stress can also lead to disruption of circadian rhythms⁴⁰, which can lead to sleep disturbance and thus to a significant allostatic load. The normal rhythmic pattern of cortisol secretion is lost and with it, ACTH levels drops much slower after activation, so the body remains in a state of prolonged alarm (Jacobson et al 1988), a further example of allostasis.

11.1.3. Inflammatory Processes

The emergence of AD may also be due to an uncontrolled inflammatory process in reaction to the appearance of amyloid-ß protein complexes in the brain (Heneka et al 2013). Neuroinflammation is associated with an activation of microglia, which remove dead or altered cells, thereby changing the architecture of the brain. Systemic inflammation elsewhere in the body may lead to an escalation of

³⁹ brain-derived neurotrophic factor

^{40 24-}hour rhythms

neuroinflammation via higher concentrations of proinflammatory cytokines in the blood.

Chronic inflammation also causes illness behavior characterized by symptoms like lethargy, depression, anxiety, loss of appetite, drowsiness, reduced pain tolerance, and concentration problems. These also occur in dementia related behavior (Holmes et al 2011). Based on these data, vaccinations were developed to achieve active immunization against dementia. Because of unexpected serious adverse effects the vaccines were not added to the therapeutic assortment for dementia. On the basis of vaccination in a randomized placebo-controlled trial in humans, amyloid-beta (42) protein plaques were removed, however, without affecting life expectancy or cognitive decline (Holmes et al 2008).

11.1.4. Two Hypotheses about the Cause of Dementia

To date, there are two hypotheses that explain how dementia might develop.

- In Chapter 10, the amyloid cascade hypothesis was addressed (Hardy & Higgins 1992). Familial mutations of the APP gene have been linked to the early onset of Alzheimer's disease. The increase of Amyloid ß causes dysregulation of the metabolism of APP. This activates a phosphorylation that enables the formation of excess tau protein, resulting in neurofibrillary tangles, neuronal death, and dementia. This is an example of an *altered metabolic process*, partly due to genetic factors.
- This chapter introduced the neuroinflammation hypothesis. In response to the onset of amyloid ß, inflammation occurs. Chronic systemic inflammation plays an important role in this through the presence of proinflammatory cytokines in the circulation. The concentration of cytokines determines the severity of the neuroinflammation. The influence played by the rest of the body makes this hypothesis more *interactional in nature* and less linear than the cascade hypothesis.

Chronic stress, chronic inflammatory processes, and shifts in the circadian rhythm are major risk factors for the onset of dementia. In general, chronic stress leads to a proliferation of the alarm center of the brain, the amygdala, and atrophy of the hippocampus and prefrontal cortex. The resultant negative neuroplasticity is greater when there is a history of more major events at a

younger age (Davidson & McEwen, 2012). It is uncertain whether the stress of negative past events can be amended. Prevention from the stress-perspective can be promoted through a healthy lifestyle (10.1.3.), in combination with meditative techniques (11.2.1.)

11.2. Traumatic Events in the Life Story as a Risk Factor for Dementia and Resilience

Sometimes it seems as if he knows everything and understands nothing (Geiger 2012)

11.2.1. Introduction

The experiences of life express themselves directly in the ever-changing architecture of the brain (see also Chapter 13). This applies to both the effects of positive and negative events. We can favorably affect neuronal networks by promoting neuroplasticity. Neuroplasticity can be promoted by regular, moderate-intensity physical activity, cognitive therapy, and by interventions derived from ancient meditation practices such as mindfulness-based cognitive therapy (MBCT) (Davidson & Mc Ewen 2012).

In this context the search for a new definition of health by the WHO is interesting to note and was first mentioned in Chapter 8. The enormous increase in chronic diseases all over the world, among them dementia, was an important reason to look to change the original WHO definition of health from 1948. The existing definition ignores the option to actively influence health. The proposal for a more active definition of health is: 'the ability to adapt and self-manage' (Huber et al 2011). Aging, or rather an older age is the single greatest risk factor for dementia (Lovestone 2009).

Is it possible to create an option for further development in some areas during the dementia process, even though the person's over-all capabilities disintegrate and control is being lost?

11.2.2. Resilience, Sense of Coherence, and Self-Control

The concept of **resilience** is closely connected to the new active definition of health. Psychological resilience refers to the ability to cope with adversity and stress, which inevitably occurs in life, in

a productive way. To develop resilience, a certain level of mental and emotional fitness must be present from a young age.

One important faculty is the **sense of coherence** (Antonovsky 1979). The sense of coherence is not defined as a coping mechanism⁴¹. The sense of coherence consists of three components, which can be activated together in difficult situations. These components are: 1) the ability to understand events in your life and reasonably predict what will happen in the future (**comprehensibility**); 2) the confidence that you have the resources necessary to find an appropriate solution (**manageability**); and 3) the belief that there is good reason or purpose to what happens (**meaningfulness**) (see also 6.1.1. and 7.3.). Although important aspects of the sense of coherence are developed in youth, it is also possible to develop it further in adulthood (Franke 1997). In an incipient dementia, coherence may be a hard thing to learn, but the sense of coherence that was developed throughout the course of life can be recruited in times of duress.

Self-discipline, the ability to postpone reward, control impulses, and modulate emotional expressions, is a similar concept. A cohort of 1,000 children was followed for 32 years. The capacity for self-discipline in the fifth year of life proved a predictor of good physical health, the absence of addictions or criminal convictions, and a healthy financial situation in adulthood. (Moffitt et al 2011). These findings held their significance after taking into account differences in IQ and social class.

These findings provide the evidence that resilience and self-control are especially important for the prevention of dementia.

11.2.3. Dementia and Society

If the current trend continues, the Netherlands will have nearly 18 million inhabitants and half a million people with dementia in 2040. Dementia is a contemporary disease characterized by 'disintegration.' Geiger posed in 2012:

"Talking about Alzheimer means talking about the disease of the century. By coincidence, my

⁴¹ stable strategies or psychological characteristics, which can be used in case of stress

father's life is symptomatic of this development. His life began in a time when there were numerous solid pillars in society (the family, religion, authority structures, ideologies, roles of husband and wife, fatherland), and concluded in dementia at a time that Western society had long found itself among the ruins of that kind of societal pillars."

Most of the time, the person with dementia is dependent on the environment to initiate meaningful contact. If caregivers are able to let go of the fixation on how communication ought to be and are prepared to respond to whatever arises in the moment, the dreaded distance to the person with dementia can be reduced and the effort can even lead to renewed and meaningful contact (see Chapters 2-6). This attitude also shows next of kin how the contact can be further deepened.

11.2.4. Trauma and Memory Curling up

Development at the beginning of life seems inversely related to that of the end of life (7.3.). In the first years of life, children have to learn to control their body (Schoorel 2009) and to come to grips with their increasing consciousness. This development runs parallel to the stages of maturation of the nervous system. During the dementia process, the decline is accompanied by a loss of contact with the body, loss of brain matter, and the 'curling up' of memory, in which events that were previously forgotten come to the fore. This can pertain to earlier trauma or stressful experience and applies particularly to events in young adulthood and childhood.

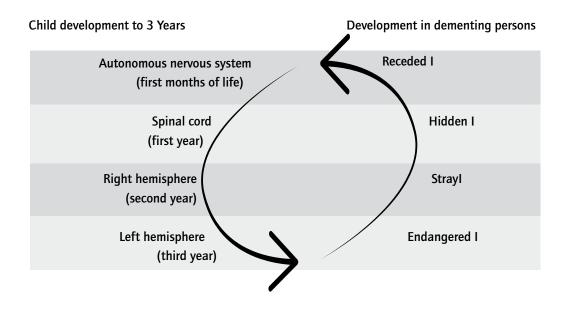
Could previously unprocessed experience play a role in what we externally observe as behavioral and psychotic problems in dementia? The four stages of dementia that Feil introduced in 2010 can shed light on this. Compared to the dynamics of the first three years of life (Schoorel 2009; Schore 2009; see also 7.3.) it is striking that in dementia the opposite takes place: the curling up of life's memories.

- In the first months of life, the *autonomic nervous system* of the child tunes in to that of the caregiver. The first phase of contact through warmth, comfort, and nourishment teaches the child to find basic forms of internal equilibrium. This stage is mirrored in the final, fourth stage of the process of dementia: the inactive phase, in which only tactile contact, attention, warmth, comfort, or just silence can be offered.
- In the second developmental phase, the young child develops the ability to hold head, torso, and back straight and to learn to deal with gravity (sitting and walking). The *spinal*

cord plays a central role in this process. This phase is mirrored in Feil's third phase when loss of communication via speech results in just motor communication through repetitive movements. The learned complex motor skills of speaking disappear and only simple, reflexive movements remain.

- In the third developmental phase of the child, the educator affects the then dominant *right cortex* of the young child through non-verbal communication (voice pitch, touch, singing), which lays the foundation for a secure bonding. The loss of emotional control in the second stage of dementia is associated with anxiety and depression and may be related to the reliving the non-integrated events of life.
- In the fourth phase, at age two and a half to three years old, the *left hemisphere* becomes dominant when it comes to brain regulation. Along with it, children enter into period of more active and focused communication with their environment (through language, thought, investigating). The beginning of the dementia process, with the loss of intellectual faculties and memory mirrors this stage of development of the left cortex.

Figure 11.1. Child development and development in dementia



The mirroring of events at the beginning and end of life may give insight into the slow unfolding of the dementia process, in which the 'curling up' of the biography is central. This may allow one last opportunity at integrating past events as well as the dying process.

11.3. Summary and Conclusion

Both trauma and life events, (stressful events such as moving, the death of a close relative) especially in childhood and youth, create an increased risk of dementia later in life (Charles et al 2006; Yaffe et al 2010; Qureshi et al 2010). Intervention to deal with these life events is also still recommended for people with dementia (Flannery 2002).

It does not seem far-fetched, on the basis of the inverse dynamics of the dementia process in comparison to the development of the child in the first three years of life, to assume that previous trauma affects the behavior of the person with dementia. The described four phases provide targets to find therapeutic interventions, which are linked to one of these four stages. Administrators of active intervention techniques should definitely consider the benefit of the visual and musical arts (see Chapters 2-6), in addition to validating techniques (Feil 2010) Careful consideration on the part of the caregiver to the phases of dementia and their related problems may help the individual with dementia to smoothly move through these phases and to potentially allow development. Old and unconscious patterns coupled with unprocessed traumatic events can still be brought to a form of acceptance and resolution. Some researchers (e.g. Feil 2010) find that this averts the person with dementia from entering the inactive phase.

12. The '4-step' Approach in Gaining Insight into Dementia by Christina van Tellingen

In Part II of this Companion, to allow for individual diagnostics and personalized treatment, we first clustered symptoms and then risk factors for dementia. The previously applied principles for clustering of risk factors in the Companion 'Depressive Disorders' (van Gerven & van Tellingen 2010) according to McHugh (1998 and 2006) also proved useful for dementia. The four clusters: structural, physiological, psychological,; and biographical factors, offer a comprehensive and practical organization of the features that play a role in normal aging (7.3.-7.6.). These clusters each cover a specific biological system:

- The first cluster is related to neuro-anatomical structures (like the brain) that can lodge visible physical and genetic abnormalities (7.4. And 10.1.). These features represent **structural physical factors**. For treatment, McHugh uses the 'disease perspective' for this cluster;
- The second cluster is based on altered neurophysiological and neurochemical processes. The abnormalities are to be found in **altered metabolic patterns** of, for example, neurotransmitter metabolism which are also found in diabetes, hypertension, hypercholesterolemia, smoking, depression, and lack of exercise (7.5 and 10.2.);
- The third cluster concerns changes in messenger systems such as the stress axis on which **psycho-emotional factors** are dependent. Chronic stress may result in disruptions in the fine-tuning of the stress axis (McHugh), resulting in an altered, allostatic equilibrium (7.6. and 11.1.). Over time this can cause brain damage;
- In the fourth cluster, the influence of **life events** is central, particularly the extent to which they are integrated or not in the life script of the demented person (7.3. and 11.2., see also Chapter 1, Mr. A). McHugh refers to this as 'negative events.' The ability to actively change the own circumstance to achieve a new balance, heterostasis, is at stake.

Each system of clustered factors needs its own approach to treat the disrupted balance that has

ensued, as we also noticed in discussing the four different phases of dementia found by Verdult and Feil (Verdult 2003; Feil 2010) based on the practice of working with older people with dementia:

- The first phase describes how the demented person is about to lose **the script of their life**, especially in Alzheimer's, due to memory loss. This phase corresponds to the development of the left hemisphere in the 3-year-old child (11.2.4.). From this time on we normally *remember life events* (Gerhardt 2004).
- In the second phase, *anxiety, panic, and desperation* are important elements of the experience of dementia. Feil calls this the emotional phase when **psychological function** changes drastically. And when the toddler learns to communicate with speech, the right hemisphere becomes temporarily dominant (11.2.4.).
- The third phase of dementia refers to *repetitive movements*. Feil speaks of the motor phase referring to changing ingrained **movement patterns**. In the young toddler learning to establish its own movement patterns like walking, the development of the spinal nerves with *reflexive patterns* takes place (11.2.4.).
- The fourth phase of dementia sees the demented person *bedridden and double incontinent*. Communication is possible through direct touch, smell, massage, and heat application. Communication is mainly limited to **physical sense impressions**. In the baby, this corresponds to the qualities of touch, *warmth, nourishment* and the development of the autonomic nervous system (11.2.4.).

Can further processes be found in which these four biological systems, structural physical factors, metabolic/movement physiologic factors, psycho-emotional factors, and life-script-related factors are addressed?

When studying living organisms, the researcher may come upon the realization that life processes are universally present in four levels of organization.

In embryology, for example processes occur in the first 24-28 days that also can be identified as occurring in four phases: the germinal phase of the first 6-7 days; the growth phase in the second week; the formation of an inner organ system in the third week until approximately day 20; and the phase of neoteny, when human development is slowed down compared to fourth week embryological developments of similar creatures eventually resulting in a longer overall lifetime

and allowing continuous development (van der Bie 2001).

In the description of the wound healing process four stages are usually mentioned, which can be retraced to the aforementioned biological systems (van der Bie et al 2008).

The clustering of four risk factors based on the four biological systems proved helpful in depression (van Gerven & van Tellingen 2010).

After meeting these four processes again and again in our studies of different biomedical subjects, we coined the work with them the '4-step' approach.

Four steps can also be found in an approach to individualize diagnostic procedures while listening to the patient's story (Intuitive Methods, van Tellingen, manuscript 2015):

- careful observation of the structural physical appearance of the patient;
- recognizing (movement) patterns during observation of the patient;
- becoming aware of how psycho-emotional factors like sympathy and antipathy impact the practioner based on the observation of the patient and patient-therapist interaction;
- allowing an intuitive idea or impulse regarding the diagnosis and/or treatment to emerge based on the original observations and in relation to the biographical events in the life of the patient.

Becoming aware of the organization of life processes into four biological systems levels can also contribute to individual diagnosis and personalized treatment.

Part III Special Themes

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Summary of Chapters 7-12 and Preview of Chapters 13-16

Part I of this Companion revealed that **some form of development and contact is possible in every phase** of the dementia process. Part II presented a vision of aging and diagnosing dementia, and discussed clustering dementia risk factors to more effectively apply personalized treatment options. Processes of **aging and dementia have much in common**. One could perhaps speak of dementia as an accelerated and intensified aging.

The progress of dementia is not only determined by anatomical, physiological, or emotional/psychological factors, but mainly by the **degree of activity or inactivity of the I** (7.7. and 8.6.). The 'use it or lose it' principle (8.2.) is strongly influenced by early life experience and social and mental activity. Resilience, sense of coherence, and self-discipline may play an important role in recovery processes in aging.

Ageing (7.3.) and also dementia (11.2.4.) have a reverse developmental trend compared to the development of the young child. The 'curling up' of memory accentuates this reversal. Earlier events can therefore come into sharp relief (11.3.).

Dementia appears to be a multifaceted syndrome with different types that partially overlap each other and that may co-occur. As such, probability diagnostics seems more appropriate than sharply defining syndromes.

Preview of Part III

In the subsequent chapters, four special topics are addressed:

- the plasticity of the central nervous system;
- terminal lucidity;
- changing brain architecture and the mind;
- the relationship between brain and consciousness.

Chapter 13 is about (neuro)plasticity and shows how repair processes work in the brain. The idea that the brain is inaccessible to the environment and functions in splendid isolation has long been abandoned. What we are witnessing one moment expresses itself in changes in the architecture of the brain the next, which is also the case in the demented brain. This means that recovery processes are always possible. If dementia is equivalent to pathological aging, an imbalance between recovery and pathogenic factors is suspect.

In Chapter 14, attention is given to terminally lucidity. This subject is mostly neglected in scientific literature. In terminal lucidity, people seem to lose their symptoms by the end of their life for a few hours or days. Sometimes they can say goodbye to their loved ones in a clear and conscious manner. This phenomenon is described in several disease entities as well as in dementia. This special phenomenon raises fundamental questions regarding the treatment of dementia.

Chapter 15 studies how the brain could function as mediator between mind and body based on its continuous architectural changes. Evolutionary data such as the development of association areas in the brain are discussed. The development of the abundance of association areas in humans characteristically creates a *time interval* between sensory input and output reflex, allowing a choice regarding the output.

Finally, Chapter 16 discusses the relationship between brain architecture and consciousness.

13. Brain Plasticity by Arie Bos

13.1. Introduction

In previous chapters, the plasticity of the brain was mentioned several times (7.5.1., 8.4., 11.1.2., 11.2.1.). Less than fifteen years ago it was generally thought that the brain had no reorganization nor regeneration potential after youth. Since then, it has become clear that at every possible occasion the brain reorganizes itself (13.2. and 13.3.). In some places stem cells have been demonstrated in the brain that produce new neurons upon recovery from depression (Mahar et al 2014). We also see this phenomenon in dementia where new neuron production is thought to take place. In this chapter, brain plasticity will be described in detail (Jin et al 2004).

The term 'brain plasticity' is used for two different phenomena:

- for the trail of new network connections between axons that every new thought, every observation, and every skill leaves behind in the brain;
- for the recovery of function after brain tissue damage, because other brain areas take over the tasks of the damaged tissue, e.g. in the acquisition of injured sensory functions by other sensory areas.

Both forms of plasticity are of great importance for rehabilitation programs.

In fact, plasticity is the core business of the brain. We ourselves plastically form our brain, as the subtitle of the book 'The Synaptic Self' by neuroscientist Joseph LeDoux suggests: How Our Brains Become Who We Are (LeDoux 2002). Without this plasticity, we could not learn or develop.

13.2. Plasticity Through New Growth and New Connections

The first phenomenon of plasticity begins in the womb as the fetus experiences the rhythm of the mother's language and perceives the taste of her food, which subsequently appear familiar after birth. The creation of new connections and the outgrowth of neurons are promoted by neurotropic hormones as BDNF, which are produced in the brain itself. These are generated with every new experience and we see that a rich environment appears to stimulate brain growth in animals just as the expression of (mother) love by caressing and cradling can also alter brain chemistry and neuronal connection.

In Romania, at the time of dictator Ceausescu, a tragic real-life experiment occurred in orphanages that showed how important a rich and loving environment is. The children were in cots with high partitions and caretakers only would hand them their bottles, without any further attention. The neuro developmental result of such a situation we see in Figure 13.1.

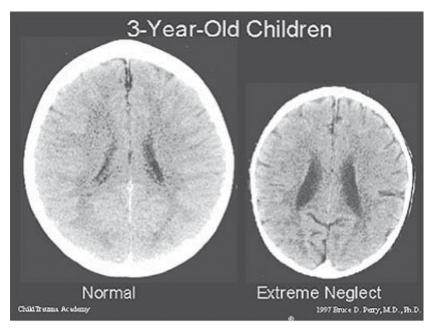


Figure 13.1. Brain development in normal three year old children (left) and in extreme neglect (right) (Perry & Pollard 1997)

It is clear that not only the orbitofrontal cortex has undergone abnormal development, but also that other parts of the cortex and that the ventricles has increased in size in addition to the grooves between cerebral convolutions. Clinically, the children showed all stages of mental retardation caused not by inborn error, but by neglect. The size of the skull simultaneously expresses how cerebral growth determines the development of the skull.

In 1949, the principles of this form of plasticity were predicted by the Canadian psychologist Donald O. Hebb (1949), who suggested that learning is based on the creation of new connections between neurons. When two neurons simultaneously fire (synchronous firing), their connection becomes stronger: "Neurons that fire together, wire together". If they do not repeat the synchronous firing again, their connection disappears: "neurons out of synch, fail to link". Later this was simplified to *'use it or lose it.*' Every activity of consciousness leaves a trail in the brain.

13.2.1. Plasticity of the Hippocampus

A special place in this process is occupied by the hippocampus. This curved structure (see fig. 13.2.) plays a significant role in memory, spatial orientation, and stress management. The plasticity of the hippocampus is greatly enhanced by locally present stem cells that grow into new neurons (i.e. neurogenesis) by thousands every day, while most of them die again within a few weeks. However, they stay alive when they are presented with a function. London taxi drivers, whose job requires that they mentally imprint the street plan of the city to their brains, including knowledge about one way traffic situations, were studied and appear to have larger hippocampi than a control group (Maguire et al 2000).

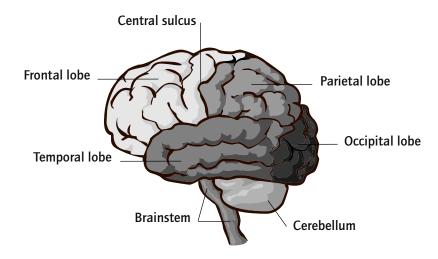


Figure 13.2. The anatomy of the brain

13.3. Plasticity via Taking over Lost Function

This second form of plasticity has to do with recovery of the functionality of nerve tissue. Two subtypes can be distinguished:

- recovery of function after damage to a functional brain area within that area or
- acquisition of certain (sensory) functions through a brain region that is normally used for other (sensory) functions.

Both forms are best illustrated by the history of the family Bach-y-Rita (Bach-y-Rita, 2013).

13.3.1. The Contribution of the Bach-y-Rita Family

In this section, we will take a critical look at the work of neuroscientist Paul Bach-y-Rita. He experimented with using particular senses to take over the work of other non-functioning senses,

such as touch impressions that produce visual experiences.

It has been known that blind people use their visual cortex to process non-visual impressions of the environment. Sensations in their fingertips and the sense of touch that is conveyed with their cane are processed in the visual cortex and *not* in the area for touch in the cerebral cortex. Mirculously, this does not require years of learning. Keen-sighted volunteers that are blindfolded for a few days and try to learn Braille soon exhibit the same activity in their visual cortex (Amedi et al 2005). In addition, sounds with which blind people orient themselves are represented in the visual cortex (Khamsi et al 2005). When you say "run", for example, this word is associated with a visual connotation linked to the movement of running. Blind people appear to activate the same brain regions associated with 'seeing running away' (the left middle temporal gyrus) as sighted people (Bedny et al 2011). In short, the blind process visual information in the same (visual) brain area as normally sighted people (Bedny et al 2012).

Paul Bach-y-Rita designed a type of lollipop with 400 spur-electrodes that were connected with a camera on the forehead. The electrodes function as 'pixels.' When a blind person lays this lollipop

on his/her tongue, they learn in a short time, because the tongue is replete with nerve endings, to 'see' with their tongue (Bach-y-Rita 2012). In the BBC television program Focus, (normally sighted) presenter Michael Mosley could, after half an hour of practice with blinded eyes, use this lollipop to throw darts at a target. They all ended up on the disk, not far from the mark. Mosley said he experienced the tongue stimuli in the same way as if he visualized a given sensation. This accomplishment was also associated with the fact that the sensory information of the tongue was processed in the visual cortex.

Figure 13.3. The lollipop of Paul Bach-y-Rita (Bach-y-Rita 2012)



13.4. The Brain That Rewires Itself?

The personal history of Paul Bach-y-Rita shows a clear reason to be intensively and systematically engaged with plasticity.

In 1958, when he was 65 years old, Paul's father Pedro Bach-y-Rita, a professor of Spanish at the University of New York and a poet, had 'a massive stroke.' He could not move or speak. He was admitted to the hospital, where he was kept in bed for four weeks, after which he was sent home in exactly the same condition. His son, the future psychiatrist George, who was still a medical student at the time, brought him to his home in Mexico. During his training, George had not yet been introduced to the prevailing belief that nothing could be done to amend this state. He conceived that his father had to learn all over again much like a baby does, which meant crawling first. George for example threw something on the floor and said, "Dad, go get it". They had a garden which father Pedro very much liked, so George organized this new training regimen in the garden, much to the chagrin of onlooking neighbors.

But dad made progress and after a while, he could walk upright supported by a wall. He also learned to talk again, do the dishes, type on the typewriter, and returned to work three years later. He subsequently remarried and worked for another five years. He died in1969 at the age of 73, of a heart attack while he was climbing high in the mountains of Colombia at 9,000 feet. The neuropathologist who performed the autopsy later published the report in the American Journal of Physical Medicine (Aguilar 1969). It appeared that the devastation in the brain stem obviously caused by the stroke was still present and much larger than expected: 97% of the connection between the cerebral cortex and spinal cord was permanently destroyed and also a large part of the motor cortex turned out to be dead! This means that his recovery from his stroke was due almost entirely to a reorganization of the little remaining and still-functioning cortex, an example of the first type of recovery of functions. As a result of this experience, son Paul, the neurologist, focused his research on neuroplasticity and rehabilitation of people with brain injury. Before he designed the aforementioned 'lollipop,' he started with coarser instruments that gave stimuli on the back. This also worked well, but was impractical.

This recovery process is commonly referred to in neuroscience as the brain rewiring itself, analogous to the title of the book 'The Brain That Changes Itself' by Norman Doidge (2008). But the question

remains if this describes the situation appropriately. Does the brain rewire itself? Is the brain the actor here?

Pedro Bach-y-Rita, after all, came back from the hospital just as handicapped as when he went in. After all, his brain just took no initiative to change anything until George decided to intervene. His dad was greatly encouraged by his son, and also mobilized a great determination within himself to change his brain. His recovery effort did not repair his dead brain cells, but it was able to activate the cerebral areas that have no special task to take on new tasks. These areas are called the 'quiet brain areas', and the neurosurgeon can remove tissue from here with impunity.

Without the stimulation of the person him/herself—enhanced I activity—the brain does not recover by itself.

13.4.1. Plasticity and Learning Difficulties

Norman Doidge (2008) also describes the case of a woman with learning difficulties. She could not understand metaphors and abstractions, did not understand the difference between top and bottom or right and left, and could not tell the time. The relationship between the large and small hand of the clock was imperceptible to her. She could not follow conversations, movie dialogues, and had to read texts twenty times and learn them by heart to be able to use them. So she developed an incredibly good memory, worked her way through high school, and then went to college. When she read about neuroplasticity, she self-imposed a strict regime of exercises. She made a large number of cards with a clock on it, each with a different time. A friend wrote on the back of the cards what time was indicated by the clock. She practiced for hours and hours on it, again and again, until she could recognize at a glance the time indicated by the clock.

The surprising thing was that her other disabilities also improved. She now has a school for children with learning difficulties. Her case is about someone who, without the help of others, but via enhanced I activity, was able to changed her own brain. What remains striking is that progress in one area can implicate progress in other areas.

Here again we see the brain learning new skills and activities because the subject perseveringly trains it to do so.

13.5. Plasticity and Aging

When there is no brain disease at play, the brain cells survive until death. At 115 years old, Hendrikje van Andel's autopsy showed that her brain was completely intact. After the age of fifty a volume reduction occurs, which accelerates after the eightieth year. The brain becomes 5 to 10% lighter between the fiftieth and eightieth year of life. After eighty, the volume decrease becomes even more severe. The volume reduction is due to shrinkage of neurons, reduction of myelin around the fibers, and probably a reduction of small nerve fibers. An additional reason for volume reduction is the fact that the neuroneogenesis decreases by 80% in the elderly.

The amount of white matter in the brain determines the speed with which we can integrate information. The decline of myelin will therefore, in addition to a decreased transmission speed of electrical impulses, entail a deterioration of the functions of the involved areas.

The volume reduction takes place primarily in the frontal cortex, in the hippocampus, and the part of the cortex that it covers the hippocampus: the gyrus (para) hippocampi (Aleman 2012). The frontal cortex is important in managing executive functions: organizing, planning, initiation, staying on course, controlling impulses, regulating emotions, adapting, and recovering (Aleman 2012). The hippocampus plays a role in the (semantic and episodic and, therefore autobiographical) memory. These are the features that suffer most when we age. The hippocampus has no function in the procedural memory that is involved in automated skills. These therefore remain intact longer with age.

Elderly people can compensate for the decline in function by training their brain (13.6.), using the phenomenon of cerebral plasticity. It turns out that neuronal plasticity in the healthy elderly can respond in (at least) two different ways to anatomical loss of brain cells and white matter.

• Larger quantities of neurons are activated for the same tasks than before, in addition to the neurons in the affected areas. Where young people use only focal areas of the brain to complete a task, the elderly may, in order to accomplish the same task, use more parts of the brain, situated in the same hemisphere or even portions of the other hemisphere. You can guess that the elderly have little 'reserve' as a result when performing rigorous tasks and then suffer from a decline in cognitive performance. This is known as the CRUNCH (compensation-related utilization of neural circuits hypothesis) model (Reuter-Lorenz & Cappell 2008).

• Older people can partially lift the relatively strict separation between the functions of the left and right brain through training (13.6.), causing the asymmetry of brain activity to decrease, especially in the frontal lobe. This is known as the HAROLD (hemispheric asymmetry reduction in older adults) model (Cabeza 2002). The elderly use corresponding regions in the other hemisphere to accomplish tasks in addition to normal regions of the brain.

13.6. Plasticity and Training

All forms of neuronal plasticity are evoked by physical, psychological, or spiritual activity of the person in question. The person's environment can assist in this process. In patients with MND⁴² it became clear that memory training clearly increases brain activity in the frontal areas, the hippocampus, and the gyrus (para) hippocampi. fMRI⁴³ scans showed this to be due to the effect of both the HAROLD- and CRUNCH model.

When these patients, in addition to a decrease in gray matter⁴⁴ in the said areas were shown with imaging techniques to also have a reduction in volume of the parietal lobe, it was found that the predictive value of this technique for the onset of AD was significantly increased (Jacobs 2011). Memory training achieved an increased activity of the right inferior parietal lobe in these patients. Healthy (younger) controls in contrast showed a decline in parietal lobe activity after training. This turned out to be based on increased efficiency, whereas the increased activity in MND patients is based on compensation. Said patients were found to have surprisingly good plasticity (Belleville, 2011). And, despite the fact that in AD patients amyloid ß protein is responsible for impeding synaptic plasticity (Shankar et al 2008) these patients were also found to still have brain plasticity (Someren & Swaab 2008).

A review shows that physical activity significantly reduces the risk of dementia. Physical activity keeps neuroplasticity primed and leads to an increase in volume of the frontal and hippocampal regions (Erikson et al 2012). There are several explanations for this. First, exercise is good for heart and blood vessels and thus also for the oxygen supply to the brain. Another possible explanation

⁴² minor neurocognitive disorder

⁴³ functional magnetic resonance imaging, a type of brain scan visualizing local brain activity

⁴⁴ outer part of the brain where cells are predominant

may be found in the fact that aerobic training (intensive enough to sweat) stimulates the production of IGF⁴⁵, a growth hormone. This growth hormone passes the blood-brain barrier and stimulates the growth of nerve cells and their connections (Gregory et al 2013).

13.7. Conclusion

We are constantly learning and thereby changing our brain chemistry and subsequently, the brain enables us to put theory into practice. Plasticity of the brain not only ensures that we can learn, but also that we 'let our brain be who we are' (LeDoux 2002). That means that by way of our conscious awareness and the use of our muscles we can shape our brain and not vice versa. We are not our brain, but our brain is ours.

The paradox is that our brain has to be healthy to allow us the opportunity to keep it healthy in turn. In dementia such maintenance becomes difficult. An AD patient no longer has access to the cognitive capabilities and the initiative to do what helps the brain restore itself. Once there is damage or decline, this is only possible when someone else takes on the task to get the patient into a cognitive and athletic training program that can stimulate neural recovery. With such attention and perseverance, it appears that even in dementia some neuroplasticity is still available. Whether consciousness indeed operates independently of the brain is further discussed in the next chapter.

45 Insulin Growth Factor

14. Terminal Lucidity by Arie Bos

14.1. Introduction

The concept of terminal lucidity is the phenomenon that demented or otherwise mentally or cerebrally handicapped people sometimes experience in the last hours or even weeks before they die, when they suddenly regain their normal mental and cognitive abilities and memories. Some recent review articles have collected dozens of case studies (Nahm & Greyson 2009; Fenwick 2011; Nahm 2012). They describe cases of schizophrenia patients who, sometimes even after having been catatonic for decades, suddenly exhibit normal behavior in the last days before they die. The same has been described in dementia. When they are in a state of terminal lucidity, patients speak with their care givers and visitors, prepare their funeral, and manage the details of their inheritance. The following are two examples:

- The first case is about a mentally disturbed and violent ex-lieutenant of the Royal Navy who suffered severe memory loss that went so far that he did not even remember his own name. On the day before he died, he suddenly became totally reasonable and asked to see a priest. The patient spoke intently to priest and expressed the hope that God would be merciful to him. The autopsy revealed that his cranial cavity was filled with so much straw-colored liquid that the ventricles were greatly distended and the little remaining brain tissue was hardened.
- The second example comes from someone who reports on the case of his brother who was living in an institution with a severe psychiatric disorder. One day he received a telegram from the director of the institution informing him that his brother wanted to talk to him. He immediately went to visit him and was astonished to find his brother in a perfectly normal state. On departure, the director discreetly entrusted to him that his brother's sudden lucidity was an almost sure sign of his impending death. This proved to be true. Autopsy on his body disclosed that his brain was full of pus and must have been in this state for a while.

Elsewhere a case was described of a patient with meningitis who was "severely disoriented until shortly before her death," but came to herself just minutes before she died, "cleared up, answering questions, smiling, and slightly euphoric" (Osis & Haraldson 1997). In 1975, two psychiatrists reported on three cases of schizophrenic patients that came in remission immediately before their death (Turetskaja & Romanenko 1975).

14.2. Terminal Lucidity and Dementia

Terminal lucidity can occur in dementia. In 2004, three cases were reported. In all three, patients had not recognized their family for years; but just before death, they were completely back to normal and able to recognize their family (Grosso 2004).

Geriatric physician Marie-José Gijsberts, co-author of this book, experienced an amazing case of terminal lucidity. This is the story in her words:

The patient was admitted to a psychogeriatric ward of a nursing home. She had a moderate neurocognitive disorder, with awareness of her illness and grief about it. Besides dementia she had metastatic rectum carcinoma, for which she has had radiation therapy. She has a stoma, which she found very difficult to accept. She was a sweet, unassuming lady who was grateful for any moment of genuine attention. She liked to sit in her room and found it difficult to face the dementia of others, and thus the situation in which she now found herself. In addition, she was preoccupied with her recent divorce and she regularly verified with her children whether it really happened. During her stay, she processed the divorce and was able to recognize it. During the months that she is in the nursing home, she physically deteriorates as a result of the cancer and becomes pre-terminal. Her children are involved and often present. On a Tuesday, at the end of a working day, I make a visit to find her comatose and comfortable. Two of her children are there with her and we briefly speak about her situation, all convinced that she would die soon.

The next day I am off, and on Thursday morning my first call is to her room. I find her quite clear, sitting up straight in bed, and she greets me. I look at the children present and they tell me that she was comatose until Wednesday around 5 pm when she woke up and told her children that she wanted to say goodbye to her ex-husband. He comes within half an hour. I'm still there at her bed talking with her when she suddenly looks up and says "he's here." Indeed, there are footsteps in the hallway, and a moment later he arrives. I leave the room, and then the children leave as well. They tell me that when she awoke from her coma it took them by surprise, as does the autonomy and persistence with which she arranged this farewell. Her ex-husband was there for about half an hour. An hour later she deceases.

14.3. Brain and Consciousness

The cases described above are just case reports, yet there is a certain consistency between them all. The described patients have not been lucid for varying amounts of time when they become clear, aware, and seem to take agency of their lives for a limited time before their death. Often, it is clear that the brain is more or less diseased before the event, or this is found afterward at autopsy. As a family doctor, I myself also experienced a dying man who, due to the metastases in his brain, was not approachable for a longer time period, and shortly before his death was clear for a short time. Terminal lucidity is obviously a difficult subject for studying patients in large groups and it is completely undetectable with the fMRI. As such, one will always have to rely on case histories. At the same time, these experiences seem to elucidate the relationship between brain and consciousness, which we may think we understand fully, but yet remains a mystery.

Current neuroscientific knowledge cannot explain these cases. Clear awareness should indeed not be possible with such a ruinous state of the brain. However, plentiful research shows that the loss of brain tissue may not result in major cognitive consequence.

The American psychologist Lashley taught rats to find their way through a maze. Then he removed a portion of the cortex and again let them walk through the maze. The more cerebral cortex that was removed, the more trouble the rats had finding their way; yet this occurred with no clear relationship to the localization of the removed cortex (Lashley 1950). Eighty percent of the visual cortex could be damaged without major visual handicaps for the rats. In cats, 98% of the optical tract could be cut without serious consequence for their vision. Even the combination of both interventions had little added effect on 'visual recognition behavior' (Pribram et al1974).

These studies may have little applicability to humans, but nonetheless, cases are known in which brain scans reveal a similarly impossible state of the brain in people who have a completely normal and clear consciousness.

14.4. Do You Really Need Your Brain?

In 1980, an article appeared in Science with the provocative title 'Is Your Brain Really Necessary?' The author interviews John Lorber, British professor of pediatric neurology at the University of Sheffield and a member of the Nobel Prize Committee, regarding his fifteen years of research into hydrocephalus in children and adults (Lewin 1980).

The article begins with the case of a young student of mathematics at his university with a verbal IQ of 126 and a performance IQ of 134, who has the highest grades in his class and is socially perfectly normal. He was referred to Lorber by the campus physician who considered his head slightly larger than usual. Lorber did a brain scan. He found that instead of the 4.5 cm brain tissue that is normally present between the wall of the ventricles and the surface of the cortex there was just a thin shell of a "millimeter or so." It was difficult to gauge how much his brain weighed, between 50 to 150 grams, "but it is clear that it does not even come close to the normal 1.5 kg." His skull was mostly filled with cerebrospinal fluid.

This young man is one of the more than 600 cases of hydrocephalus that Lorber collected. He came upon it via his specialization in children with spina bifida⁴⁶, which is often associated with hydrocephalus. Cerebrospinal fluid⁴⁷ (CSF) is secreted from the walls of the ventricles and circulates through the ventricles via the spinal canal to the bottom of the spinal cord after which it flows upwards along the outside of the spinal cord to the outside of the brain. In the arachnoid sheath⁴⁸ it is then reabsorbed into the blood. When an obstruction occurs somewhere along this tract, the CSF cannot be reabsorbed and the ventricles dilate under the increasing fluid pressure. When this occurs in early childhood, the skull increases in size, which was the typical presentation of patients

⁴⁶ spine open to the outside

⁴⁷ fluid that surrounds brain and spinal cord

⁴⁸ one of the meninges

with hydrocephalus in years past. It is less common now owing to better pregnancy checkpoints. But sometimes by chance a child with hydrocephalus is found with a skull of almost normal size. We speak of an 'internal hydrocephalus.' This usually leads to obvious handicaps, but not always. Lorber classified his case histories into categories of increasing 'fluid volume' (Lorber 1983). Of those with 95% CSF in the cranial cavity, which is 10% of the 600 cases, half of these people are severely disabled but the other half has an IQ of over 100! The latter cases with a high IQ probably differ from the first in the fact that the hydrocephalus is much slower onset and thus more time is present for neuroplastic adaptation.

Another group of patients that Lorber studied had unilaterally enlarged ventricles. He has registered more than fifty patients and only a few showed the expected contralateral cerebral palsy. The case of one of the unilaterally paralyzed people flies in the face of one of the most certain things we think to know about the nervous system: the crossing of the nerves as they extend to the body. The paralysis was in fact located on the same side as the enlarged ventricles. Lorber owes his knowledge about these cases to brain scans. Because the subjects are still alive at the time of his investigation, the pathologic-anatomical macroscopic or microscopic structure of the brain is not known. It is clear that the normal mapping of brain regions is not applicable here. Research in cats with an artificially induced hydrocephalus, for example, shows loss chiefly in the white brain matter and hardly in the gray. The number of neurons is not reduced, but the myelin sheaths around the axons⁴⁹ are reduced. The myelin sheath is seen as essential for quick transmission of action potentials and thus for intelligence.

Since Lorber published his article in 1983, a number of further cases has been reported.

A French officer, for example, married and with two children, felt weakness in his left leg. Incidentally, he has an IQ of 75, adequate for his work and family life (Feuillet 2007). CT and MRI scans showed the following picture:

^{49 &#}x27;insulation' around the fibers of neurons

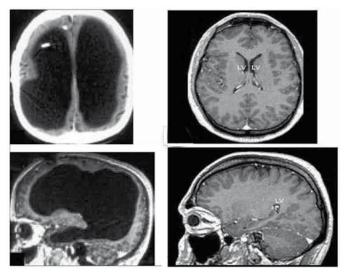


Figure 14.1. Images of the patient's brain are on the left while a normal CT image is on the right for comparison (Feuillet 2007)

14.5. Half Is Sufficient

Other examples of massive absence of brain tissue without notable effect are known in intractable epilepsy. Intractable epilepsy has tempted neurosurgeons into doing radical things in the past. Callotomie⁵⁰ resulting in split-brain patients is no longer done (see 15.3). Hemispherotomy⁵¹ is still occasionally done in epileptic children up to ten years, who curiously enough often remain cognitively intact (Kossof et al 2003). When they are young enough, removing the left hemisphere does not negatively affect speech, however the left visual field is disturbed and the left-hand side of the body may be paralyzed (Choi 2007). A story that is not found in scientific literature but can be found on the internet, is possibly apocryphal, but in accordance with the preceding sources:

An eight year old boy with Sturge-Weber syndrome, which is often associated with vascular abnormalities in the brain with ensuing epilepsy was very backward in his

⁵⁰ cutting through the corpus callosum

⁵¹ removal of the hemisphere where the source of the seizures is localized

development: before his operation he could just say "Mummy". His development accelerated after removal of the affected hemisphere and was soon completely normal.

(*Http://flatrock.org.nz/topics/science/is_the_brain_really_necessary.htm*)

An example from the Netherlands is a girl whose left brain had been removed at age three. At the age of seven, she spoke Dutch and Turkish fluently and showed only slight spasticity on the right side of the body. (Borgstein & Grootendorst 2002).

14.6. The Nuns Study

Another example of unexpected lucidity despite a disabled brain is found in a study of 678 nuns. Researchers in Kentucky regularly tested their cognitive functions for twelve years (Snowdon 2003). At the start of the study none of the nuns had signs of Alzheimer's. They had regularly scheduled brain scans and had previously given permission to examine their brain after death by autopsy. The scans revealed diminishing brain circulation with age in all and autopsy scarring of the brain. But the remarkable thing was that there was no correlation between the degree of shrinkage or decreased blood flow and the scores on the cognitive tests. Sister Matthia for example, at 84, was still a teacher and died at the age of 104 from cancer, remaining alert until her death. The cognitive tests in the last year before her death showed no decline. Incongruously, her brain was full of typical AD characteristics. This picture was seen in other nuns as well, while still others with less reduction of brain volume and fewer other signs of AD in their brain, did show clinical signs of dementia.

De-mentia means decline of the spirit. Where you end up depends on where you start. When going down a hill you are faster at the bottom than when you began your descent from the top of Mount Everest. The lucidity of consciousness during aging seems to be more dependent on the quality of consciousness itself, then on the quality of the brain.

14.7. Conclusion

The fact that there is a form of consciousness in above examples of terminal lucidity and in situations where a large part of the brain is removed or destroyed debunks the idea that the brain is solely responsible for consciousness. The examples rather seem to indicate that consciousness has its own dynamic, operating independently of the brain. They show that clear self-awareness is still present in one way or another, even when the state of the brain does not really support its manifestation, as is the case in dementia. Thomas Fuchs describes this in his book 'Das Gehirn-ein Beziehungsorgan' (The Brain-A Mediating Organ). He argues that it is not the brain that thinks, feels, and acts, but the living human who utilizes the brain (Fuchs 2013).

What is the connection between brain and consciousness? That is a question that still has not been answered satisfactorily by the scientific community. In the next two chapters, a cautious attempt will be made.

15. Brain Architecture and the Mind by Arie Bos

15.1. Introduction

The different forms of dementia that are discussed in this book can all be categorized as brain disease. In this chapter, we try to evaluate the role of the brain in initiating consciousness. To this end, we begin with the question whether the architecture of this organ gives insight into its function.

15.2. Brain Form and Brain Function

The first person to make an attempt to answer the question regarding the role of the brain in consciousness was the American neurophysiologist Paul MacLean (1913-2007) in 1978. Many people are familiar with his idea that our brain is made up of three parts there are 'stacked one on top of the other' during evolution.

He called the *lower part*, which consists of the medulla oblongata⁵², basal ganglia, hypothalamus, and cerebellum the **'reptilian brain'** (fig. 15.1.). Its function is completely unconscious and has to do with the preservation of life. For example, it controls instinctual fight, fright, and flight reactions as well as others.

The *middle section*, the limbic system, in this model is called the **'mammalian brain'**. This section refers to the feelings and emotions that take place in the semi-conscious mind. The limbic system includes the septum, the amygdala, the cingulate gyrus⁵³, and the hippocampus⁵⁴ (fig. 15.1.). The limbic system is connected to the hypothalamus.

The *upper part*, the neocortex, Maclean called the **'primate- or human brain'**, which is the foundation of consciousness and thinking in humans.

⁵² part of the hindbrain, continuous with the spinal cord, responsible for the control of respiration, circulation, and other autonomic bodily functions

⁵³ an old part of the cortex

⁵⁴ important for example for memory

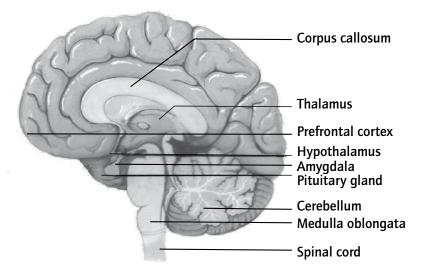


Figure 15.1. Cortex, limbic system, and 'reptile brain'. Wikipedia

This model has become known as the triune brain concept (MacLean 1978, 1990). The names reptile, mammalian, and primate brain are considered unrealistic by evolutionary biologists. Their objection is that the basal ganglia already exist in fish and amphibians, that many parts of the limbic system already evolved earlier than in the mammalian brain, and that the cortex is not an invention of primates but is already present in the earliest mammals. And perhaps more importantly, reptiles indeed have consciousness, too. However, the triune brain concept does clarify differences in function in the human brain. What this concept does elucidate is that the degree of brain development has a relationship to the level of awareness of its owner.

15.3. Tripartite Awareness

What the triune brain concept aptly shows, apart from a clear consciousness and an unconscious awareness, is a third, dreamy type of awareness that is characteristic for feeling and emotions. This indicates a tripartite framework: thinking (cortex, consciously), feeling/emotions (limbic system, semi-conscious), and acting ('reptilian brain', unconscious).

Neuro-scientific research shows that actions are usually preceded by an unconscious motivation that we only become aware of after the act. American neuroscientist Joseph LeDoux also recognizes the trinity of conscious awareness: cognition, emotion, and motivation (LeDoux 2002), or, more simply, thinking, feeling, and willing. The more highly evolved cortex areas allow us to ignore or stop the impulses of the lower areas.

But the question of whether or not and how the human cortex differs from that of our predecessors in evolution is not resolved. What happens in evolution with the relationship between brain and consciousness?

15.4. Molecular Consciousness?

The brain is needed to be able to respond to the environment. How do single-celled organisms do it?

Single-celled organisms have to preserve their internal homeostasis and the electrical potential difference across the cell wall. To survive, they must adapt their activity to the environment such that they 'know' what they need and when to maintain homeostasis. They 'know' this without senses or nerve cells, with the aid of substances that are also in use in the human organism such as neurotransmitters, neuromodulators, hormones, cytokines⁵⁵, and with molecular receptors on their cell membranes to which these molecules can attach (Hsu et all 1986; Lyte 1992; Wolosker 1999, Tsakelova 2006, Freestone & Lyte 2008). These molecules modulate the behavior of single cells.

In humans, neurotransmitters and modulators are considered necessary to be able to experience actions and feelings. What about the protozoa?

Neurotransmitters and modulators apparently also operate without neurons, much like hormones function without help of the organs that secrete them and cytokines without the immune system (Bie van der 2014). Well considered, unicellular organisms, and certainly eukaryotes⁵⁶, all have features that the rest of the animals develop further during evolution: perception and reaction, moving, digesting, breathing, etc.. An amoeba can find its way out of a maze and can help other

⁵⁵ immune messenger substances

⁵⁶ nucleated protozoans

amoeba that have problems separating from each other in the dividing process by ramming against them so they come loose (Nagasaki 2000). Slipper animalcules (paramecia) even seek out sex partners to exchange nuclear material.

Evolution can be seen as an exercise to develop function-specific organs, where protozoa have to make do with biochemistry and cell organelles. Organs have the ability to accomplish the same tasks more specifically and from a broader perspective in a more differentiated manner. Consciousness in evolution begins in protozoa as a kind of dull unicellular body awareness. The remaining question is: what kind of experience do they have along with this awareness?

What kind of awareness are we talking about? We speak about the ability of single cells to respond to the environment while preserving their molecular organization and homeostasis.

15.5. The Task of the Brain

In animal evolution, the brain appears after the sponges and polyps. It has the task to capture stimuli from the environment, differentiate the response of the body, and coordinate the processes of homeostasis. Brain function of higher organisms is more differentiated and at the same time also supports their more differentiated conscious awareness. The brain functions as mediator between mind and body (Fuchs 2013 2011).

15.6. Encephalization

In evolutionary literature, emphasis is usually placed on the increase in brain volume, the so-called encephalization, with progressive cerebral functionality. But the increase in brain size is not so interesting in itself. Larger animals have bigger brains than smaller ones. Much more interesting than the increase in mass is the greater refinement of the involutions on the surface of the brain, the increased number of connections between the axons of nerve cells, and the increase in energy consumption of brain cells. These are really the factors that facilitate the expansion of the functional capabilities of the brain.

Which brain functions have evolved in evolution? Looking at it from the perspective of mammalian evolution, the following items of interest:

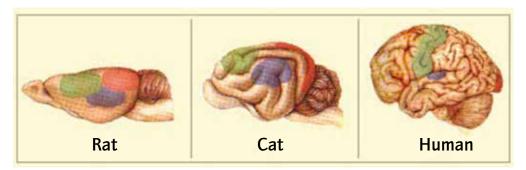


Figure 15.2. The primary visual cortex has been colored in red; the primary auditory cortex blue; the primary motor and sensory cortex area green (http://thebrain.mcgill.ca/flash/i/i_05/i_05_ cr/i_05_cr_her/i_05_cr_her.html).

In the rat, the cortex area is largely occupied by primary projection areas of the senses and the primary motor cortex area. The cat brain has additional involutions. In humans, the primary projection areas of visual, auditory, motor, and sensory cortex almost disappear in comparison to other cortex. The neocortex is amazingly expanded.

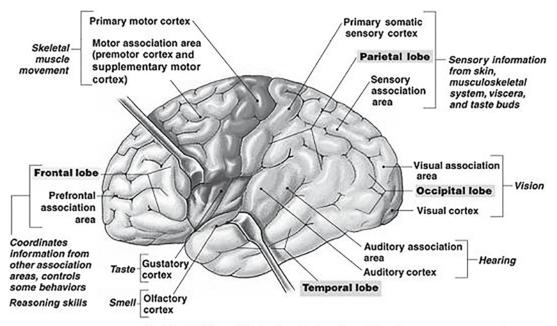
What is the function of this enlargement of the neocortex?

15.7. Association Areas

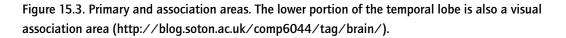
Association cortex is found in the frontal and prefrontal lobes, in parietal, temporal, and occipital lobe regions (fig. 15.3.).

The increased cortex area can be almost entirely attributed to the many association areas, especially in the prefrontal cortex. The task of the association cortex is pattern recognition, which enables us to **give meaning** to sensory impressions and actions.

The entire brain evolutionary development can in fact be considered as continued attempt to evolve beyond the immediate automated reflex response following sense impressions; in



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essence brain development attempts to increase the time lag in between perception and action.

As a result, we should be open to the opportunity for a different kind of conscious awareness. Something has (physically) appeared in the space between sense impression and reflex, the association cortex, such that the process takes more time. *This offers the possibility to inhibit, give meaning to the sense impressions, and modify reactions.* A free space is created for conscious awareness, which increases the possibility of considering how the reaction to said sense impressions could best be shaped. In other words, particularly in humans who have the most association cortex, room is created to give attention and significance to the sensory impressions and to take into consideration how to best react. It is not insignificant that this meaning-giving has to be learned.

15.8. Tripartite Cortex

Because the human cortex generates free space for conscious awareness by increasing the amount of association area, humans have acquired naysaying ability to counter automatic and reflex responses that are provided in older, lower centers.

What does the naysaying look like?

In fig. 15.3., behind the central sulcus⁵⁷, we can see the somatosensory cortex (indicated in blue), where direct sensory perception is processed. Directly in front of the central sulcus is the motor cortex (shown in red), which directly represents body movements. These two brain regions represent consciousness of the body. Both sides of the divide have much to do with each other (fig. 15.4.).

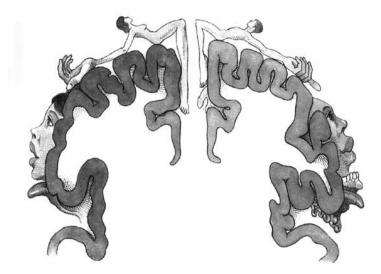


Figure 15.4. A cross-sectional view of the left hemisphere. On the left, the motor area in front of the central sulcus: the female figure symbolizes the localization of the motor movements. To the right is the area behind the central sulcus: the male figure symbolizes the somatosensory localizations (Posner & Raichle, 1995).

⁵⁷ groove running across the middle of the brain from left to right

As a result, three areas can be distinguished in the cortex. These areas represent the three areas over which the naysaying consciousness reigns.

- The association areas of the posterior and temporal cortex are devoted to naysaying consciousness in relation to exploring the world through the senses.
- On either side of the central sulcus, we find the representation of somatosensory and motor consciousness of the body. This is not association cortex, and is not involved in 'naysaying'.
- The association areas of the prefrontal lobe are separated from somatosensory motor body consciousness and consciousness of the surroundings by the the frontal border of the motor cortex area and remain 'detached' from them, in both a physical and symbolic sense.

The prefrontal lobe can "take its own course offline", independent of input from other areas, and it is particularly the naysaying association area that distances it from them by delaying nerve conduction of reflex motor reaction in response to sense impressions.

The frontal lobe is situated next to the motor cortex, which controls motor impulses.

Naysaying consciousness is principally localized in the prefrontal cortex. It assures that human behavior needs are not exclusively determined by environment and body needs only and that people are not simply deferential their environment or passions. The space that is created as a result of naysaying can be compared to the distance one has to another person. Humans recognize themselves as self among other selves as a result of the distance to others. Humans experience the functions of the frontal cortex as belonging to their innermost self: it leads to the experience of l-consciousness.

From the posterior cortex to the frontal lobe, we successively find areas that represent the awareness of the environment, of the body, and of the inner self. This does not mean that these respective areas operate in isolation. There are many neuro-connections back and forth and no task is done by just one brain area. Every cortical activity activates also an interconnected network to and from other brain areas.

15.9. Development of Frontal and Temporal Cortex

The frontal lobe has expanded amazingly in humans. In dogs, it takes up 7% of the brain volume, in monkeys 17%, and in primates and humans 35%. What do primates do with their frontal cortex? We know that they do much less with their frontal lobe than humans. This stems from the fact that primates have less association cortex and less overall cortical volume.

15.9.1. Genetic Changes in the Brain

More differences in the DNA of brain cells occur in humans than in primates, which gives rise to more possibilities for frontal cortex use. Our brain cells contain many more **transposons**⁵⁸ than other tissues. This has the effect that **our neurons can all differ in their genome**: Each neuron has about 80 to 300 unique gene mutations. "It seems as if every cell is there with a purpose," says neuroscientist Alysson Muotri of the University of California at San Diego (Owens 2012). Such differences are always results of challenges in the (cultural) environment. This means that, as long as our brain maintains plasticity, we are always able to adapt to cultural changes. We, in turn, initiate these cultural and environmental changes, which means that our brains are most likely different from those of our ancestors.

Evolution is not always, or even often, the result of random mutations that offer a better chance of survival. Organisms seem able to adapt their genome, their DNA, and themselves⁵⁹ to their environment. We can adapt both to *changes in our environment* and to *changes in our own behavior*. Epigenetic changes can account for certain **genes being turned on or off**. This results in a change in the biochemistry of the cell⁶⁰ but does not alter the composition of the genome (or the underlying DNA sequence. When epigenetic signals are persistent and become more compelling via permanently changed behavior, (that may be due to the changing demands of the environment –also a form of stress), just bringing a particular gene to expression may not prove sufficient. Then, the **gene is duplicated** (Perry 2008). Genes may also **change places on the chromosome**

⁵⁸ jumping genes

⁵⁹ In contrast, random mutations usually have no effect or mean bad news: they are responsible for genetic disease. They rarely provide improvements

⁶⁰ the discipline that studies these phenomena is known as epigenetics

or be recombined. It appears that the location of a gene on a chromosome matters much in terms of activity (Chen et al 2013). This cut, paste, and copy function only occurs with environmental stress⁶¹. The genome is rewritten so that it takes on a different function. This has nothing to do with random mutation.

Genes constantly interact with the cell and with the entire organism. They cannot do anything on their own. The genome of any organism contains elements that can trigger the above changes (duplication, relocation, recombination): transposable elements or transposons . It took a long time for the existence of this process to penetrate into the field of biology As early as the 1940s, Barbara McClintock discovered this first, even before the double helix structure of DNA was found⁶². She noted that corn under stress can alter its genome (McClintock 1950). She was silenced for almost thirty years by the scientific community because of the controversy of her discoveries until other scientists began to see similar findings, (Bauer 2010), but ended up winning the the Nobel Prize in 1983 for this groundbreaking work⁶³. The topic continues to be hot in cell biology (Pennisi 2007). When it was then shown that such changes could be passed on to offspring⁶⁴, the end of previously held evolutionary dogma was imminent (Jablonka and Lamb 2005).

It is not accidental which genes are candidates for duplication and other benchmark changes. Transposons occur near genes that may be epigenetically altered without causing problems or that may even offer benefit. Genes that must remain in their primal form due to an essential survival function remain immune from changes mediated by these transposons. In normal, stressfree environments the transposons can also be suppressed.

Five hundred and fifty million years ago, the lead in intelligence that vertebrates would eventually assume over lower organisms was ushered in when two duplications of the gene encoding the structure of synapses occurred. These were not random mutations. Random mutations in these genes actually lead to psychiatric disorders according to Nithianantharajah et al 2013 and Ryan TJ et al 2013. Of interest is that an organism can develop genes that are not useful for it at present, but that may come to expression when a new species evolves. This is called exaptation.

⁶¹ fortunately, otherwise there would be no continuity of species

⁶² in 1953, by James Watson and Francis Crick

⁶³ her Nobel Lecture 'The Significance of Responses of the Genome to Challenge' can be read at: http://www.nobelprize.org/ nobel_prizes/medicine/laureates/1983/mcclintock-lecture.html

⁶⁴ by RNA interference (See: Bauer J. Das Kooperative Gen. Evolution as Kreativer Prozess (The Cooperative Gene. Evolution as Creative Process) Munich 2010. And: Bos A. Hoe de stof de geest kreeg (How Matter Got the Spirit) Zeist 2008

Another example of spontaneous genomic changes as a result of specific stress in larger organisms is the following: humans have 98.7% of their genes in common with the chimpanzee. The 1.3% difference is arguably due to the activity of transposable elements, which mainly encode for brain, sense, and immune system differences. That is where humans are generally better off. For example, of a specific gene (called SRGAP2) the chimpanzee and other mammals only have one, while humans have four copies. This gene ensures the production of synaptic connections and guarantees that humans have many more connections in their brain (Dennis et al 2012) than primates. *Is this cause or consequence of human culture?*

15.9.2. Myelin Formation and Brain Development

At least as significant is the fact that apes have less white matter, fewer nerve-axons, fewer connections, but most importantly less myelin⁶⁵. Myelin formation in the frontal cortex in humans begins after birth and is completed around the 25th year of life.

One part of the frontal cortex, the orbitofrontal cortex, is not present at birth The orbitofrontal cortex is fully existent ten months after birth and, initially, mostly on the right side. Between six and twelve months, explosive growth occurs in the prefrontal cortex and in the fourth year all neurons are finally present, while primates have all the neurons they will get at the time of birth. In addition to the prefrontal cortex, the temporal cortex including the hippocampus that it surrounds is also not operational until the fourth year of life. Memories of before that time are rare and most experiences during this period imprints the lower brain centers (Gerhardt 2004). This means that those memories can affect behavior but are not accessible to the memory.

The growth of the still immature cortex after birth is entirely dependent on the interaction between the child. its parents and/or care givers (section 13.1). When this is non-existent or insufficient, the development of the brain and of the child is stunted (see fig. 12.1.). With aging, the same law applies in reverse: last in, first out, which is to say that the part of the frontal cortex that was formed last loses its volume first (cf. 11.2.4.).

⁶⁵ the white matter surrounding nerve fibers, which, inter alia, ensures that the transfer of nerve impulses is much faster and therefore has great impact on intellectual abilities

16. Brain Architecture and (Self-)Consciousness by Arie Bos

16.1. Say "No"

In the previous chapter, the naysaying ability of the brain was discussed in relationship to brain architecture (15.8.). An important function of neurons in the cortex is inhibition⁶⁶. Inhibiting neurons are amply present in the brain. The frontal lobe has the most powerful naysaying function relative to the area behind it. Naysaying is an integral part of the structure and function of the triune brain: brain functions related to the upper part of the brain tend to suppress lower ones (see section 14.2.). We have also seen that frontal areas suppress posterior areas (15.8.). And it seems that the brain also makes use of the third facet of three dimensional space - left versus right (16.2.).

16.2. Two Parties

The division of the brain in a left and a right hemisphere that each are connected to the contralateral⁶⁷ side of the body, is a striking phenomenon. The left hemisphere is responsible for the activities of the right body and vice-versa. The connection between the two hemispheres takes place in the corpus callosum (fig. 15.1.), which implies that the left hand indeed knows what the right hand is doing. When that connection is broken by predisposition, illness, or callotomy⁶⁸ we speak of 'split-brain' patients (see also 14.5.). In these patients, one might observe their left hand buttoning a shirt, while the right opens the buttons again, which points to the so-called 'alien hand' syndrome.

The corpus callosum connects left and right cortex halves via 300-800 million fibers. A significant

67 crosswise

⁶⁶ the suppression of further conduction of nerve impulses. This is done with the neurotransmitter GABA (gamma-aminobutyric acid) in the synapse, which results in a reduced electrical activity of the following nerve

⁶⁸ an operation to correct persistent and comprehensive epilepsy

portion of these neurons is not excitatory but rather inhibitory. That means that one hemisphere can put the other on the sideline, like the winning party in a country with a two-party system. Naysaying is therefore a three-dimensional process in the brain. From top to bottom (cortex versus lower centers, 14.2.); from front to back (frontal lobe versus the rest of the cortex, 15.8.); and left to right, and vice versa. Functional naysaying in the brain allows humans to live in the consciousness of freedom: 'free unwilling.'

16.3. The Assignment of the Two Hemispheres

We once thought that the left hemisphere was mainly concerned with language and the right with spatial orientation. In fact, the two halves are *engaged in the same reality*, each in a different way. Otherwise it would not be possible that both hemispheres are called upon to perform a task. (see 12.7.). However, both hemispheres originally have different ways of performing tasks.

There is a macroscopic, structural difference between the two hemispheres. The right hemisphere is thicker with more, larger neurons, and contains more branching and more connections than the left. There is more white matter on the right suggesting more global, faster connections, while the left has more local connections (Scots Thiebaut et al 2011).

What are the consequences of the structural difference between the hemispheres in terms of functionality?

Intelligence is determined by brain development and the opportunities this gives. The hemispheres are each an instrument for their own kind of intelligence: the left hemisphere supports linear, serial thinking and the right is like a parallel processor (Bolte Taylor 2006).

This is an evolutionary determined difference, since animals have two mutually conflicting goals that need to be met in relationship to their environment: the first objective is finding food; the second is not to be eaten.

Take for example a chicken. To eat, it ought to focus on something it recognizes as edible, something familiar and of edible size: not too big—something like seeds, leaves, and insects. In other words:

details. In animals with laterally placed eyes the left eye sees the left visual field and the right the right field. These are each projected in the contralateral visual cortex.

In order not to be eaten, the chicken also keeps an eye out to the world to be prepared for the unexpected (a buzzard in the air or a fox in the distance, etc.) That cannot be done simultaneously with the same eye. Chickens have contracted one task to each of their eyes and use the right to eat and the left eye to monitor the environment.

That means that a chicken's left hemisphere is concerned with detail and what is already known and the right with context, the whole, and the unexpected. This also applies to other animals and, for example, to humans. In humans, the left hemisphere is not the only one that adheres to speaking. The right hemisphere also contributes to the meaning of what is said. Humans take things literally and they stick to what is known when they work with their left hemisphere; the right, thicker hemisphere allows for experiencing the unexpected of metaphors and poetic language and the search for hidden meaning.

Animals that can use tools such as the crow, use their right eye and left hemisphere to apply them. This hemisphere is specialized in manipulating, cutting into pieces, and analyzing. The right hemisphere leaves the whole—the context—intact.

Humans can apply this division to concepts as well. The left hemisphere abstracts, and that it only understands an object when it is compared to something that is man-made. The thicker right hemisphere tries to understand the organic nature of things and synthesizes the information to create a cohesive whole. The left hemisphere facilitates the reductionist thought processes and the right facilitates holistic thinking (McGillchrist 2009).

For the left hemisphere there is only one truth, which is the truth that we all know, while the right hemisphere is able to hold contradictory ideas with equal emphasis. The right hemisphere, for example, has no trouble holding the conviction that all people are equal and yet at the same time hold the belief that all people are different. Because the left half can suppress the right, the left hemisphere can latch on to a theory with vehemence unadjusted by the right hemisphere, even when it is not conform reality or common sense. The left hemisphere—that will be clear when we look at the whole picture—tends to tolerate only one truth and is intolerant of dissent. This is also an interesting fact in looking at aging and dementia. The right hemisphere becomes the predominant sphere as people age, as was described for the CRUNCH and HAROLD-models (13.5.). *Could this also be related to the fact that older people sometimes speak such wise words, even though they have less cortex?*

16.4. Tickling the Cerebellum

A usually neglected part of the brain that completes much of the work of the cerebral cortex, should also be mentioned here: the cerebellum, which lies underneath the occipital lobe (fig. 15.3.). The cerebellum also has two hemispheres, and contains 80% of the total quantity of neurons in the brain! The cerebellum enables humans to automate movements and plays a role in their smooth and coordinated progression. This applies principally to movements we have mastered by practice and that henceforth are initiated automatically.

The cerebellum also has the ability to suppress other brain areas. When we tickle ourselves, for example, the cerebellum suppresses the reactions that might arise when someone else tickles us.

As such, cerebellar damage actually results in being able to get yourself to giggle when you tickle yourself. Cerebellar damage also results in *cerebellar ataxia*⁶⁹. Involuntary reflexes, such as the eye-blinking reflex, run via the cerebellum. The cerebellum plays an important role in such sensory functions as proprioception⁷⁰ and equilibrium. Less immediately understandable is the fact that damage to the cerebellum disturbs the capability to estimate the time as well as the memory, which holds functions such as the short term recall of a telephone number.

Since other parts of the brain share functions (16.3.), it may not surprise us that the cerebellum, which had initially restricted itself to body functions as part of the 'reptilian brain,' also plays a role in more conscious cognitive functions. Cerebellar damage can also bring about psychological disorders, such as dyslexia, ADHD, impaired verbal intelligence, and learning disabilities (Swaab 2011).

⁶⁹ it with a finger

⁷⁰ perception system with which one becomes aware of the position and positional changes of one's body

Although plaques and tau proteins typically associated with Alzheimer's are not found in cerebellum disorders, this region of the brain also appears to experience similar repercussions to this progressive disease. In both vascular dementia and in AD there is a marked reduction in volume of the cerebellum (Baldacara et al 2011), which keeps pace with the clinical signs (Sjöbeck & Englund 2001). It is quite possible that many of the symptoms of dementia are due to the reduction in volume of this brain area (Sui & Zang, 2012).

16.5. I-consciousness and the Binding Problem

Brain scientists describe how different brain areas represent specific body parts or perceptions of the outside world (see also fig. 15.4.). The question that needs to be asked in relation to this is: *represent, for whom or for what?*

Different aspects of bodily or environmental perception (visual, tactual, auditory, etc.) are connected to a particular moment in time—the here and now—yet travel different pathways, all of which have different time cycles and localize to different brain areas. The actual time difference may be as much as half a second. *How do they come together as a whole picture?*

That question is called **'the binding problem.'** The place in the brain where that happens cannot be located. The riddle is usually solved by assuming that the brain creates a construct in 'the present' from this information for it to coincide in the 'here and now,' based on the assumption that the brain produces conscious awareness. For Lamme, it is the reason to call the 'now' an illusion (van der Heyden 2013), as well as I-consciousness, whose location in the brain has been sought but never found. Many neuroscientists consider the I and the here and now illusions just like Lamme (Lamme 2010). The I is for them no more than the story we tell ourselves about ourselves, as a result of the fact that we also experience others as independently acting unique persons, with their own motives (Dennett 1991).

What does that mean for the endangered, lost, hidden, and submerged I? (see the introduction to Part I) Is there no I-consciousness?

Antonio Damasio sees it differently. He exemplifies the idea that humans can only have conscious

experience if they have an I that is able to experience events. He believes that not only humans but also some primates and other animals are capable of this. Awareness of our body creates the basis of this sense of continuity, which is characteristic for the I, according to Damasio.

When is a person aware of their body? It starts every morning upon waking and every evening it ends at bedtime. The nuclei that regulate this awareness lie in the medulla oblongata close to the central canal. They are called the 'peri-aquaeductal gray' and for Damasio, are the neural correlate of the self (Damasio 2010). When a stroke or bleeding occurs in the dorsal part of the brainstem, the specific consequence is coma or a vegetative state.

However, pathological incidents in the ventral medulla oblongata result in the locked-in syndrome in which the person in a coma has normal consciousness, but cannot express themselves. The question is therefore: *does someone who is in a coma or in a vegetative state have an I?* And *what about the people, without locked-in syndrome, who are in a coma and seem to have no form of consciousness?*

This also brings up the next questions: does a correlate of the self exist in the brain? And, are consciousness and I tangible concepts?

Another concept is worth looking at in this context.

16.6. Daydreaming and the Resting Brain

The American neurologist Marcus Raichle examined what happens in the brain when it has no tasks—when a person stares into space and daydreams: the brain 'at rest'. It appears that brain activity does not stop when there is no focus, but becomes concentrated in a few regions of the cortex. These regions use as much energy when the brain is at rest as the other areas do at times when the brain is 'at work.' Raichle calls this the default mode network (DMN, Raichle 2001). It is active by default when the brain is not concerned with anything else. The remarkable thing is that the more active the rest brain network is, the more random thoughts (thoughts without obvious external cause) a person has (Mason et al 2007).

The DMN is situated in several brain areas: the medial prefrontal cortex, which we use, among other things, to get a picture of what goes on in other people; the parahippocampal gyrus⁷¹, the rear portion of the cingulate gyrus and the nearby part of the cortex called precuneus⁷²; and the remainder of the parietal association cortex⁷³ (see fig. 16.1.).

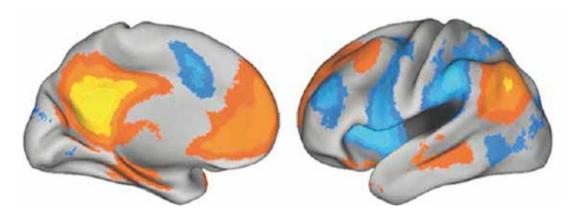


Figure 16.1. The association areas of the default mode network are orange/yellow. On the left the medial side of the left hemisphere. On the right the lateral side.

Figure 16.1. specifies more than just frontal lobe involvement in what we previously mentioned as our 'innermost' self (section 15.8.). The main area is found on the medial side of the two hemispheres deep in the slit between these and on the medial side of the temporal lobe. Speaking of innermost...

What keeps the resting brain busy? Daydreaming or which is also called the flight of ideas, thoughts that naturally come and go, the wandering mind, the stream of consciousness. These may be memories plans, assessments of self or others, etc. This description of the resting brain is remarkably similar to the concept of self that Lamme (2010) and Dennett (1991) employ (16.5.).

⁷¹ this lies immediately above the corpus callosum and is highly influential in linking behavioral outcomes to motivation (e.g. a certain action induced a positive emotional response, which results in learning)

⁷² this plays a role in self-reflection and episodic memory-the story of one's life, non-spatial processing, and waking consciousness

⁷³ this is used to associate sensory impressions to spatial orientation.

Researchers that first discovered the DMN, think that the task of this network should be sought in the preservation of conscious awareness of self, which represents the inner world. When the brain gets a task, in short when a person focuses his/her attention on something else than themselves, the DMN halts. Humans lose themselves on the job, literally.

Again one area suppresses the other and vice versa.

Only in depressed people do thoughts of worthlessness constantly fill the consciousness and remain present in all activities. DMN does not stop them (Sheline et al 2009, Raichle 2001). Mindfulness training has been shown to be helpful in mediating these thoughts (van der Hurk 2012). **Awareness can stop an activity of the brain**.

The brain is clearly always at work, even at night. In this respect, it is similar to the lungs since breathing goes on as long as a person is alive. At the same time, this does not prevent people from having control over the breathing. We can halt the DMN by actively focusing our attention on something.

16.7. DMN and Dementia

Signs of early AD are found in the DMN (Greicius et al. 2004). Alzheimer plaques in the brain occur when the protein APP⁷⁴, and the enzyme BACE-1⁷⁵ converge. These ingredients are separated in healthy brain cells but come nearer to each other with increased electrical activity especially in the DMN! (Das et al 2013). Therefore it follows that the healthy person should attempt to limit the activity of this network and learn to focus the mind.

Perhaps this explains the phenomenon of the nuns study (14.6.). The nuns who had enough mental stimulation to keep their brain active and were able to focus their attention, showed the least clinical signs of dementia even though they had extensive pathological anatomical features of the disease. The DMN is only active when the person is 'absent-minded.' This seems pertinent terminology. It is conceivable that artistic therapy in various stages of dementia can be employed by mobilizing different levels of 'presence', so the DMN is addressed less frequently (see chapters 2-5).

⁷⁴ amyloid precursor protein

⁷⁵ beta-site APP cleaving enzyme

16.8. Conclusion

Knowledge of the functions of the brain regions to some degree gives insight into the nature of the symptoms that occur in the various forms of dementia. This does not have to mean that deterioration or failure of a particular region cannot be (partially) reversed by neuroplasticity (Chapter 13). The loss of a lot of brain tissue can occur while at the same time the individual maintains self-conscious awareness (Chapter 14). This begs the question of whether consciousness is of the same order of reality as is the I, as well as whether the I is more than mere brain activity.

We researched neuroscience in vain so far to answer the question about *whose* consciousness and *whose* motivation we are speaking of. The fatal mistake of the 'homunculus' is soon uttered: the idea that there is a little person in the brain that sees what performances the brain stages, that pulls the ropes in our minds, that reads the input and sends off the output: a typical pejorative caricature among neuroscientists. The problem with this idea is that if we apply our understanding of multi-layered consciousness, then the homunculus should have yet another little man in its head, and so on.

In the journal *Nature* of November 6, 2013 an anonymous article was published by a young professor in neuroscience (Anonymous 2013). He says that he has been diagnosed with Parkinson's disease. He publishes anonymously because he does not want to put his scientific career in jeopardy. Many colleagues think that Parkinson's disease is irrevocably linked to cognitive decline. He describes how he sometimes cannot lift his arm even though there is nothing the matter with the arm.

"Occasionally, when I attempt to lift my hand it well ... won't. Notice that I didn't say can't. There is nothing wrong with my arm. It is still strong and capable of moving, but I have to put effort, even focus, into getting it to move—frequently to such a degree that I have to pause whatever else my brain is doing (including talking or thinking). [...]

The way my mind and body do battle forces me to reconsider the homunculus [...] Virtually all that we know about how the brain is organized belies this image, and yet *there is a dualism to my daily experience*." (Italics AB)

As long as everything seems to work, we can believe that the brain governs everything. But when the brain is no longer accommodating all situations, one can have the experience that we ourselves operate the brain. This dualistic experience points towards a different order of reality for brain activity and self-awareness.

That would mean in dementia the I/the self is still present, even though he/she is no longer able to fully express themselves. And owing to that fact, it is possible to mobilize a certain plasticity with, for example art therapy, in order to utilize what is left of brain activity as effectively as possible.

Epilogue

The chapters of Part III reflect recent discoveries and questions about the brain and self-consciousness.

The chapter on plasticity (Chapter 13) teaches us that what we used to think about the brain being 'fully-developed' at youth and only declining after adolescence now appears not to be correct at all because **each observation changes the architecture of the brain**. This allows the older person with less functional brain tissue to learn to continue to function adequately.

The chapter on terminal luminosity (Chapter 14) speaks of functional patterns of the brain and their relative independence of the remaining quantity of cortex area that allows us to learn these patterns: "Just half is enough." The real possibility that self-awareness and brain activity are not of the same order of reality sharpens the question regarding the relationship between brain and consciousness.

Chapter 15 addresses this question and concludes that evolutionary and phylogenetic development in the ongoing differentiation of the brain is associated with a greater differentiation of consciousness. The association areas are responsible for the essential increase in volume of the brain. They create a time interval between sensory input and reflex output. This delay creates the opportunity to not only connect in **reflex-like sympathy** with sensory stimuli but also to ignore them in a **gesture of antipathy: 'naysaying.'** This creates a new conscious awareness in the mind, the possibility of 'free unwillingness,' facilitated by the architecture and functional patterns of the brain, in humans in particular.

In Chapter 16, naysaying is applied to the left and right hemisphere. Coordinating time tables of different sensory impressions into a meaningful coherent picture of the 'here and now' raises the question of the I in relationship to awareness and the brain. It also appears that one can halt the resting brain or default mode network, which is active when the attention is not focused, by focusing the awareness. The default mode network is the place where microscopic AD symptoms first occur. The more active the default mode network, the more plaques. It appears that people whose brains are not fully functional can get the experience that **he himself or she herself is the**

one who utilizes the brain. This dualistic experience points unswervingly to *a different order of reality for brain activity and self-awareness.*

The view that brain activity and self-awareness are of a different order of reality essentially supports the experience of practitioners and therapists treating people with dementia as described in Part I of this Companion. Even though this is a syndrome in which the I may seem to disappear, selfawareness can unexpectedly be present in each of the four decline phases wherein the affected person can settle unfinished business (see also Chapter 14).

Dementia therefore appears to be a myth, as is indicated by Peter Whitehouse (2008), just as long as we continue to look at the structural, physical-anatomical, physiological, biochemical, and psychological symptoms. Once the question of the brain-independent I-consciousness is asked, it proves to provide exciting challenges for the creativity of relatives, care givers, doctors, and therapists that evidently offer exceptionally effective new ideas.

The chapters in Part III address the question of the relationship between brain and consciousness on four levels. They are recognizable as the four biological systems described in Chapter 12: the structural system, the functional patterns, the psyche, and I-consciousness.

The '4-step' format for the organization of different topics again proves fruitful and allows us to have a more holistic picture of the progress of disease as well as new avenues for science discovery and conscious inquiry.

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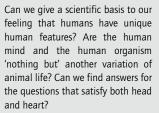
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How these questions are answered depends on the scientific method we use: the current scientific method to learn about biological facts, the *4-step* approach to understand more about the meaning of these facts, or a combination.

Early embryological development can teach us about the unique and characteristic qualities of the human being.

The result is, for example, a possibility to understand the relation between consciousness, psychology, and behavior and the shape of the body.



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What emerges is a new grasp of the interrelations between biological processes, consciousness, psychology, and behavior.



Anatomy Morphological Anatomy from a Phenomenological Point-of View

Guus van der Bie MD Publicationnumber GVO 03

Can we give a scientific basis to our feeling that the human being has unique human features? Are the human mind and the human body 'nothing but' another variation of animal life? Can we find answers for these questions that satisfy both our head and our heart?

How these questions are answered depends on the scientific method we use. In this publication two methods are used: the current scientific method to learn about anatomical facts and the *4-step* approach to understand the meaning of these facts.

Human morphology can then be understood as an expression of the unique and characteristic qualities of the human being.

This results in new possibilities for understanding the relation between consciousness, psychology, behavior, and morphological aspects of the body.

BOLK'S COMPANIONS FOR THE STUDY OF MEDICINE

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Other publications in the series:



Physiology Organphysiology from a Phenomenological Point of View

Christina van Tellingen MD Publicationnumber GVO 04

Can physiology give more insight into the living human organism than the mere facts reveal at first? Is the level of activity the same for all organs? Are the vital qualities at work in organs unique for organisms and limited to biological activity? Can we find a scientific basis to research the coherence between organ systems? By enhancing the current scientific method with the 4-step approach, we can find meaning in the facts and understand them as an expression of life itself. The 4-step approach makes the relationship between organs visible and comprehensible. It approaches scientific facts from the point of view of their coherence and can give totally new insights this way.

What emerges is a grasp of the interrelations between biological processes, consciousness, and nature.



Immunology Self and Non-self from a Phenomenological Point of View

Guus van der Bie MD Publicationnumber GVO 05



Pharmacology Selected Topics from a Phenomenological Point of View

Christina van Tellingen MD Publicationnumber GVO 06

Pharmacology gives us insight into the way organic processes change when foreign compounds are introduced into the organism. Pharmacology is a changeable subject, depending on the needs and knowledge of the time. Can we find an inner coherence in the manifold ways compounds influence organisms? What should such a framework be based on? How can we understand the effect on human consciousness that most compounds have?

We can enhance the scope of the answers to these questions by using a combination of the current scientific method and the *4-step* approach. It illuminates the known facts about the activity of compounds in organisms, and provides the means to find their significance.



The Healing Process Organ of Repair

Guus van der Bie MD Tom Scheffers MD Christina van Tellingen MD Publicationnumber GVO 07

After finalizing the series BOLK'S Companions for the Study of Medicine for the moment, this module on The Healing Process introduces a new series of BOLK'S Companions that studies the Practice of Medicine. In it, we research the healing process itself. There proved to be an enormous volume of scientific literature on the subject. It is easy to lose oneself in the countless details included in the descriptions of this process.

The *4-step* approach in systems biology makes it possible to examine physiological and pathological processes in terms of the processes themselves. This results in a characterization of the various phases of the wound healing process. Out of this, new insights into the origin of health and disease emerge that also offer possible leads for medical practice.

Why write this new booklet on immunology when there are already so many excellent texts on the subject? This Companion is about questions such as: why is it that the immune system functions as one organ? What coordinates the immunological functions?

Here, an attempt is made to develop a viewpoint to answer these questions. By using the *4-step* approach, the factual knowledge obtained through reductionism is placed in a larger perspective.

The concept that is presented in this Companion is derived from the functioning of organisms, observed in the way that was introduced by Goethe in his phenomenological method. This also includes the acquisition of insight into the holistic concept behind the immune system. Moreover, the organism as a whole can then be seen as an expression of the same concept.

NIONS FOR THE PRACTICE OF MEDICINE



Respiratory System Disorders and Therapy From a New, Dynamic Viewpoint

Christina van Tellingen MD Guus van der Bie MD (eds.) Publicationnumber GVO 08

In this Companion, the experience of three of our own patients with asthma and pneumonia is used as backdrop for the study of airway disorders. Nearly all of us have had some experience with respiratory disease, given that colds, flus, sinusitis, and bronchitis are so common. Most physicians and therapists know people with asthma and pneumonia from own experience and will readily recognize the descriptions we provide.

The experience with these patients leads us through a study of airway disease which opens up to a wider view with new insights and innovative avenues of individualized treatment for respiratory disorders in general. Our research has alerted us to the part rhythm plays in the healthy respiratory tract and in the treatment of its disease. Rhythmic processes, consequently, are the subject of the final paragraphs of this Companion.



Depressive Disorders An Integral Psychiatric Approach

Marko van Gerven MD Christina van Tellingen MD Publicationnumber GVO 09

The treatment of depressive disorders is increasingly under scrutiny. We classified the risk factors of depressive disorders according to the scientific method applied in systems biology and phenomenology. The ordering in four biological levels that resulted from this, helps clarify the causes of the disorder. Together with the developmental history, it can lead to an individualized treatment of the patient, tailored to his or her specific situation. The treatment aims at restoring the deficient forces of selfhealing.

This Companion presents a working model based on this methodological approach, as well as a variety of case histories to illustrate how applying this model can aid diagnosis and treatment in practice. Tables are added ordering well-researched regular and integral treatment methods according to the four biological levels.



Depressieve stoornissen Een integraal psychiatrisch antwoord

Marko van Gerven MD Christina van Tellingen MD Bestelnummer GVO 11

"Dit boek beschrijft op heldere wijze hoe een systematische aanpak de basis kan vormen voor een meer individuele benadering in de behandeling van depressie"

Prof.dr. Jan van der Greef, hoogleraar analytische biowetenschappen Universiteit Leiden en wetenschappelijk directeur systeembiologische research bij TNO.

Deze uitgave richt zich op psychiaters, psychotherapeuten, psychologen, orthopedagogen, paramedici werkzaam in de geestelijke gezondheidszorg en studenten in deze richtingen.

ON THE FUNDAMENTALS OF MEDICINE



Wholeness in Science A methodology for pattern recognition and clinical intuition

Guus van der Bie MD Publicationnumber GVO 10

How do you develop clinical intuition? How do physicians gain practical knowledge about disease? Diseases do not merely concern a partial defect, they recreate the life of the patient. The author shows that experienced physicians conceive of diseases as integrated concepts, which they can apply to the individual situation of the patient. Clinical intuition is a form

of pattern recognition that supports the ability to recognize an integrated 'whole.' This Companion presents practical exercises that allow readers to train and expand their ability of pattern recognition through Goethe's methodology. Questions and introspection aid to become aware of what you did. This makes obvious that clinical intuition, as experiential knowledge, can become a skill that is actively developed

To order the Companions see inside of front cover or check our website: www.bolkscompanions.com

Dementia and I

This Companion contributes to an integral approach of dementia and the person experiencing dementia. It does not close its eyes to the horrors of the disease but rather provides new perspectives to meet the process of withdrawing of the mind with courage and confidence. We know that the individual's I retreats, but it does not disappear! The classification of the withdrawal process in four phases in this book enables the environment to pursue and support the I during the whole process. As a result, the opportunity to deal with unresolved events in life is created in the dementia process.

Wouter	Endel N	1D, Amsterdam
An inspiring book for th	ie reade	r who searches
for more than one way	of lookin	g at dementia.
Wonderful stories that	penetra	te to the core,
alternating with an a	pproach	to dementia
from a developmental p	berspecti	ve. The special
attention to spiritual iss	ues at t	ne end of life is
meritorious.		
The book combines th	e practi	ce of working

with the demented individual with theoretical concepts.

Tom van der Meulen, director Ideon, dementia professionals

A special book which describes that despite brain damage, development opportunities continue to exist in dementia, and that the I can manifest itself at distinct moments, as I have also experienced with my husband. Then I saw for a moment the man he once was For me this confirms the concept of mind over matter.

Mrs. S. de Ruiter, family member