

Foreword

This practical guide on dementia by Pieter de Boer, is built on his years of experience as caregiver for his wife. It is a monumental modern mainstay in dementia care. The years that his wife already has suffered from Alzheimer's disease, have repeatedly produced new challenges at home.

Mr. de Boer is an example of how warm care, love and ingenuity can lead to solving or improving difficult situations or problematic behavior. This while the professional health care continues to stand empty handed.

The advices are not scientifically proven. But that is not the issue. Science looks for treatments that work for all patients with Alzheimer's disease. This caregiver, such as Pieter de Boer, searches for a solution for only one person: his or her partner/neighbor. If it can help them then it is good enough and pure profit for both. How it works is less important.

In the first place other family caregivers, but also professionals in care and welfare, can learn a lot from the tips that are described in this brief start guide. Not all concrete advices do work for everyone, but they are worth trying . Only then you can indicate whether they suit your own personal situation and preferences. The clear language that mr. de Boer uses in his guide is mainly based on a professional career as an instructor and coach at several multinationals. It is also based on his personal mission to help other people with dementia and people in that environment, but without the adornment of difficult words or long sentences. No nonsense, it has to help and has to tell what's important. That's what makes the difference.

Secondly , the underlying attitude is worthy to copy. Pieter de Boer continues to try to make his life with his wife as good as possible. He tries to reduce the discomfort or trouble by carefully experimenting on the approach or adaptation of the domestic circumstances. Such an attitude I really want to recommend everyone. It appears that people can do more than just rest and await. Starting points of course remain: safety and protection of the patient's autonomy, privacy and the voluntariness of the patient.

When we, as professionals, work together with caregivers, we can learn from one another by sharing practical and scientific experiences. That way we can make big steps forward in the dementia care. In short, anyone who has suffered a loss by dementia in his or her immediate environment, can win a major battle by reading these practical 'pearls' from Pieter de Boer.

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Let me introduce myself

I'm Pieter (61 years) and I am married to Grietje (60 years) for 38 years now.

We have two sons and one daughter. All happily married and a total of eight grandchildren. Grietje has Alzheimer for 7 years now. Through trial and error I have found a way to cope with this as a caregiver in a pleasant manner.

Emotionally, the last years there showed mountains and valleys and sometimes some silent crying. Alzheimer dementia is a disease that repeatedly gives emotions such as anger, sadness, helplessness. Many times I thought 'why'? After two years it looked bad and we thought that the moment to say goodbye to Grietje was coming closer very rapidly. I felt like I completely lost control and as caregiver I was sucked into the world of caretaking. Because of this, emotionally this was a turning point. Instead of just waiting and seeing how it would go, I started my fight against Alzheimer, including the fight against the huge bureaucracy and regulation . A concern on itself.



With this guide I hope to show you what things can help both patient and caregiver. But at the same time I want to be honest, the advices will not work all the time and for everybody. The core of good care taking is the mixture of experiences from the caregivers as well as from the science. Caregiving will always be a custom fit thing. Every year we will change this guide where it is needed in consequence of positive experiences from the readers.

Introduction

Why did I write this practical guide?

- To give a short and practical guide to everybody who has to deal with loved ones who suffer from dementia. How to deal with these people and how to deal with material and legal effects.
- To share the many positive experiences in dealing with these people , which can help in preventing unnecessary and unintended suffering caused by a wrong approach.
- To share the expertise from caretakers in this area with the scientists and the medical world. Through this cooperation and above all, by listening and responding to these experiences, people can learn how to successfully deal with dementia.
- To reach the media. Both the scientific and the medical world are quite unattainable. In these worlds the lessons learned from experience are easily lost and scientific research predominates. By scientists a lot is said about the target group without talking with the target group and their caregivers.
- To enter the battle with everybody who ignores the caregiving experiences, armed with huge commitment and emotional charge. Both patients and caregivers are weaker in today's society and cannot always speak for themselves.
- To show people that this summary of relevant experiences may save a lot of time and research, but also to serve patients and caregivers who are not used to working with computers and the digital network to find their own way across all fragmented advices available on different internet sites.



The five most important characteristics for a caregiver are:

- Availability
- Preparedness
- Involvement
- Familiarity
- Adaptability



Legal consequences

Once the diagnosis of dementia, in whatever form, has been established, it is wise to immediately arrange some things in the material world and to legally capture lack of representation.

For example:

- To create a testament together with a notary
- Give someone the power of attorney to make decisions on your behalf in the future

Many people only think of this aspect when it is too late. Please arrange all the legal things when the patient is still mentally competent and ask an experienced notary to inform you about all the legal consequences.

Communication

Failure and discussion

Never give the patient the feeling that he/she did something wrong (failure). Do not start discussion and / or noticeable correction. People with dementia don't make mistakes and are always right. When they ask you if they have done well, always start the answer with the word 'YES' and never (how well-meant) start with 'NO'. These two words are very important and can influence the behavior positively (the YES) or very negatively (The NO).

Constantly encourage and show appreciation of what the patient has done or told. (Even though it may not have gone very well). Trying to help or correct them (how well-meant and told in sweet words) can evoke sadness and aggression. People with dementia will notice that apparently they are not doing well enough. Realize that at an advanced stage, the (mental) health of people with dementia only decreases and they are hardly capable of learning things.



Assignments and directing

Give one command at a time and summarize it briefly. Speak clearly and repeat it if necessary. You will quickly add too much information or put too many orders in one sentence and because of that you will not achieve anything of what you wanted. A detailed explanation creates chaos in the brains and you achieve nothing. Our extra "clarifying" creates chaos.

Good examples:

1. Stand up
2. Sit down
3. Lie down
4. Lift your foot
5. Take your cup

Unintentionally bad example

If you drink this, we will go walking. (You want people to drink and then walk.)

You have to decompose the sentence in the following steps/tasks:

1. Take the cup
2. Drink it
3. Put the cup down
4. Stand up
5. We are going for a walk

Wait to appoint the next step until the previous step is performed. If you want to achieve something, socializing is out of the question.

One thing at a time

For example:

While walking, we point out a plane in the sky. For the patient this can be experienced as three actions simultaneously. 1. Walking 2. Following the finger 3. Searching the aircraft

While walking, all the attention is most likely needed to focus on the walk. If you want to show something, you have to stop first, to enable the patient



to focus on looking. People with dementia sometimes give the impression that they do see the thing you have just pointed at. They can sometimes circumvent us and create the impression that they do understand us, because they want to meet the request/order and the loved one's expectations. But if you find out they do not understand it, then you have to realize the order may need to be cut into more pieces. It is extremely important and instructive, to continuously reduce our gabbling to pointwise short instructions. The result will give a good feeling, most of the time. But please remember: **Patience is very important.**

Plans

Tell the patient a plan of action shortly before you are going to execute it. This prevents a lot of behavioral disturbances, the patient will come to rest if the performance is there. For the patient it is very annoying if you told him/her about something and they still have to wait for a couple of days. Also do not tell plans shortly before going to bed. This can cause worrying, staying awake, sadness and restlessness.

The sound of the voice

Sometimes we are in a rush and because we want to get to faster results, we try to manage this through more compelling talk, raising our voice and repeating things. But this is counterproductive and we often reach the opposite. The tone of your voice is very important and the patient can hear that something is going on. If they get the feeling they are not doing well, they will not pick up the command and they will get confused. Patience is a virtue and thus the control of your voice as well, although this can be difficult sometimes, especially when you are in a rush.



Hearing

Periodically have the ears checked by the GP (general practitioner) for possible blockage of the outer earway by earwax. If necessary, let the ears be sprayed out. Clogged ears can also be a cause of poor response. The patient cannot indicate this, but it still can severely distort the behavior. The patients will look at you with a face that shows that they do not understand you. 'Huh Huh Huh Huh Huh?' Please note that this is not typical behavior for a patient with dementia. There can be more causes for the poor response. We must realize that restlessness or deviant behavior usually has a cause and is not typical for Alzheimer's or a patient who suffers from dementia.

By sharing our experiences and thinking logically about what can cause the restlessness we can save a lot of misery for both the patient and the carer. People with dementia can remain at home longer if we take preventive actions. Adjustment in the way we approach patients is working better than medication, which most of the time also has many side effects. Communication and tact therefore deserves special attention.

In addition, special attention is needed in creating rest and regularity in the pattern of eating, drinking, sleeping and toileting. This mainly prevents the anxiety, panic, unrest and even convulsions. We will come back to this in this guide as well.



Nutrition

In the field of nutrition, there are countless advices. I only want to mention those of which we clearly have experienced the positive impacts with regards to the inhibitory effect on the dementia process.

Green tea

The substance EGCG in green tea can have an inhibiting effect on the dementia process. The tea, if prepared according to a specific procedure, ensures an optimal effect of the EGCG (antioxidant). You have to use 15 grams of lemon juice on 1500 cc hot water and 15 grams of green tea (stir-fried and no leaf pouches). The patient has to drink 1 ½ liter of this tea spread over a day. Of course one can also prepare the tea into 3 smaller portions spread throughout the day. You then have to use: 5 grams of lemon juice, 500 cc of hot water and 5 grams of tea leaves (stir-fried). I use Chinese tea called Gunpowder and regular lemon juice from the store. This provides the desired acidity, causing the antioxidant EGCG to remain effective. For those interested, there is a comprehensive leaflet about the preparation of green tea (so far in Dutch) and this can be found on the website of the Radboud Alzheimer Center in the Netherlands. **Please realize that green tea will certainly not inhibit the process of every patient, but it is definitely worth trying.**



Electrolytes

If the patient does not drink enough or their temperature is very high, dehydration and/or shortage of electrolytes can cause slowmotion in reacting. But certain solutions, like ORS sparkling tablets, can ensure that their way of reacting will get back to normal. (ORS = Oral Rehydration Solution) I have given these tablets to my wife regularly the past years and there always was an improvement. The salts are signal carriers. We sometimes also use it after a stomach flu, to get rid of the sagging feeling. When a patient drinks too much, they also get rid of salt and with dementia this is doubly noticeable.



In case of eating and drinking, you really need to say to the patient on a regular base to take the food and to take the drinks. If you do not encourage them, they will most likely not consume these. In a later stage of the disease you probably need to encourage them repeatedly to get them to finish their drinks/diner. Encourage them by saying, for example: Please take another sip.



This is doable at home, but too time-consuming and not feasible when the patient is in an institution. As a result: too little drinking and dehydration.

Breakfast

For years a number of large food companies have been working on developing products, that restrict the dementia process. Unfortunately it appears that the inhibitory compounds that are working well in fresh raw materials partially turn ineffective, after trying to make them less perishable. The price of these ready-made products generally is high.

The next (cheap) products contain materials (proven by scientists), which can positively influence different kinds of dementia. I try to process the most effective ones (if available in the shop) in our daily sandwich.

For example:

- fish oil and / or avocado, which we like to put on our bread
- Tomato
- Soft-boiled egg
- Green tea

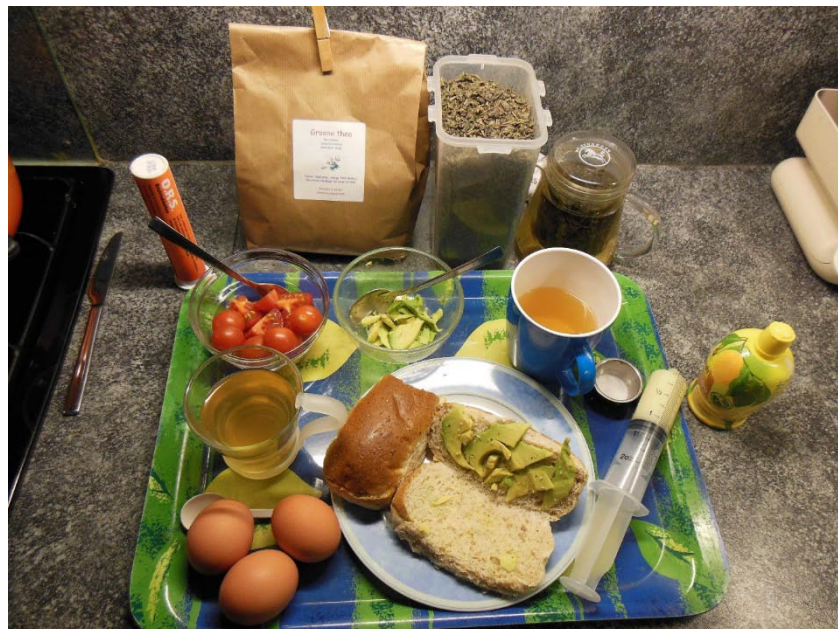
Delicious and healthy, and possibly later in the day accompanied by a glass of freshly squeezed orange juice, and in the course of the day an apple.

Fish oil (DHA ,EPA) is available in several health stores, but only one Avocado already contains the same correct oil. You have to keep the fish oil in a syringe to prevent oxidation (this happens when it gets into contact with oxygen).



In the picture below you can see our breakfast (from the top left to the right):

- ORS effervescent tablets
- A bag of green tea (one kilo, Gunpowder)
- Storage bin for green tea
- Small teapot
- Tomato, Avocado
- Soft boiled eggs
- On the open sandwich, you see avocado
- Sea salt in stainless steel bowl
- Syringe with fish oil
- Lemon juice from the store



Thirst

Patients get tired quickly and in the evening go to sleep early. In the course of the night they can get thirsty, causing them to get restless. During our holiday we had diner with our children and ate fries and a piece of spareribs. My wife really loves this. After one cup of coffee, she went to bed. While she was sleeping we took something to drink, because we got thirsty after eating these things. After a short sleep my wife became restless and unable to sleep anymore and she started to get panicked. I took her to the bathroom to pee and I opened the window in the bedroom a bit more, but this did not have a positive effect. So after one hour I took her to the bathroom again to pee, but still no effect. I asked her what was wrong, but she could not tell me. At 4 AM in the morning, I awakened because I was thirsty and then I thought about asking her if she wanted to drink some water as well. 'Yes', she sighed and she greedily drank two glasses and fell asleep again.

This was another logical signal. I automatically responded and took action, but I



did not take away the cause of her unrest. Her body continued to react because it needed something to drink, but my wife was not able to tell me and because of that the restlessness did not stop. Just like a baby, we must consider why the behavior changed. We as caregivers should signal these problems for the patient and through this knowledge and action can prevent a lot of unrest.

Toileting

Both number one and number two can cause a lot of trouble/unrest. Let the patient visit the toilet periodically (every 3 hours or when behavioral disturbances occur). The urge that they have to go to the toilet, can provide tremendous turmoil (even severe respiratory problems). Bystanders think this is a result of the dementia, but this is not true. We have to be aware that unrest, most of the time has a cause, which can be solved.

Take the patient to the toilet before he or she normally goes to bed and also in the middle of the night and the unrest will be gone in most of the patients. I would surely recommend to try this at home, because the rhythm of day and night will not be disturbed and the patient is well rested and therefore will be able to stay at home for a longer period of time. In nursing homes this is difficult to implement, but still highly recommended in case of behavioral problems during the night.



Routine

With regards to daily actions, try to operate with the same routine every time: Climbing the stairs, getting into the car, sitting down on the toilet, taking a shower etc.

Glasses

For eyeglass wearers: When the patient is no longer capable to read, than you should let the optician remove the focus/reading area in the glasses. The switching between the reading area and the rest of the glasses is very disturbing and causes the patient to put the head up and down, over and over again. It looks like they are searching for something all the time. Because of this the signal to the brains becomes increasingly disrupted.



Teddybear

It might seem childish but at home, when the partner always sleeps in the same bed as the patient, it is a good idea to give the patient a (big) teddybear when they go to bed alone early in the evening or to take a short nap. The patient is used to the fact that somebody is lying next to him when going to bed and they will stay awake when their partner did not join them. I bought a big teddybear and put the arm of my wife around this bear. It really moved me to do this, but my wife smiled and she went to sleep very soon.

Fatigue

If you see that the patient is tired, you should take him/her to bed. Even though it is not bedtime yet. For patients it is very exhausting to constantly try to follow and understand other persons and that is why patients suffering from dementia often are tired sooner. Because they are tired the responsiveness decreases rapidly. Questions are not answered well or the locomotion will falter. This can be



very difficult when you try to help the patient to get into bed etc.

Temperature

Weather

If a patient in addition to the dementia has to deal with heat in the summer or cold in the winter, this will cause unrest. It can sometimes be the cause of big problems for both the patient and the caregiver. Signals/commands are hardly getting through. People with dementia usually can not put into words what is happening. Sometimes they totally put us on the wrong track. For the caregivers this can have quite an impact physically and emotionally on the endurance. As a caregiver you will sometimes completely lose the adhesion.



When it is very hot and you do not have air conditioning, put the feet of the patient in cold water or take them to bed and take out the clothes and cover the body and head with wet towels. Evaporation of water provides cooling. Heat and cold can cause major problems and disorientation. **An air conditioner is definitely recommended.**

In the winter a room, for example the bedroom, can cool down a lot because of ventilation. If the patient is put into a cold bed, it might happen that the body is not able to bring up the body temperature. The patient becomes hypothermic and thus confused. You should really pay attention to the body temperature during the winter, check if the face or hands are feeling very cold. Unfortunately I had to learn this the hard way several times.

Music and television

For patients it is fun to listen to familiar music. Music fascinates and it makes you feel good and people with dementia occasionally hum along. It evokes emotion/memories. Also (old) well-known TV series, recordings, concerts, etc. etc. they experience that as very enjoyable.

Exercising

Walking is an excellent exercise. Adjust your pace to the pace of the patient. If the process of the disease progresses, the best thing is to take the patient's arm or hand let them set the pace.

My experience is, that I got very tired and got a tennis elbow, because I was constantly pulling my wife during our walks and therefore I even got the feeling that she was just braking. What a waste of energy. Nowadays I adjust my pace to hers and we both enjoy our walk. Please note that the orientation may completely be gone. Guiding is very important.



Illness

Health

If a patient gets another disease besides the dementia, this generally causes big problems. Signals/comments are hardly getting through. The patient usually cannot put into words what is happening. In case of gastroenteritis the patient does not know if they have to throw up or have to go to the toilet because of the diarrhea. They most of the time cannot get to the toilet by themselves. Contact a doctor and try to establish a plan of action. For caregivers this can have quite an impact on the endurance both physically and emotionally.



When I speak for myself, I find it quite difficult to contact a doctor, because it feels

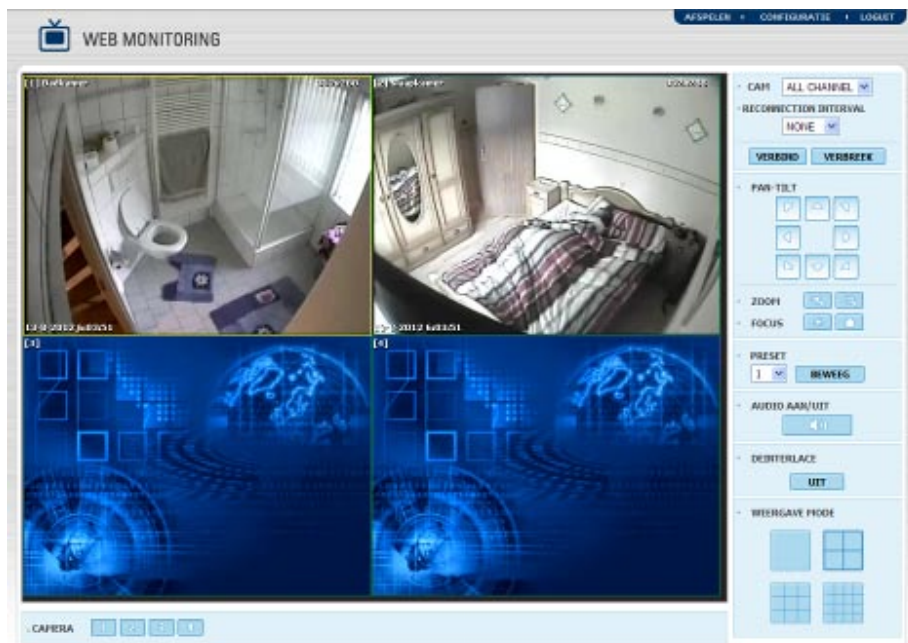
like losing control and it seems like I cannot do anything anymore. Only waiting until she gets better. Heat and gastroenteritis can cause big problem and disorientation.

Home automation

Home automation has expanded enormously in recent years. It can help both patients and care experts and caregivers to perform or monitor better and faster. The possibilities are endless, but it is best to limit yourself to what you really need. Don't get tempted by the wide range of devices offered.

Ask help from an expert (for example a case manager) and ask him/her what is the most practical in your situation. Pay attention to ease of use and operation.

Many things are computer controlled or so complicated that you will have major problems regarding the operation. Good lighting and perhaps surveillance cameras in different rooms can give rest to the caregiver. Via the computer, mobile phone or tablet, there is constant supervision from where you are located. You can signal unrest immediately. Please see the picture below.



Light

In all the rooms there should be clear and constant light. Differences between light in several areas can sometimes cause anxiety, doubt and sometimes the patient blocks. The patient does not trust it, because it looks different or they cannot see clear enough. Even the difference between daylight and artificial light can stop the patient from entering a room.

Colors

Household objects

Make sure there is a significant contrast in color and shape between the object and the surroundings (for example the table). The discernment will decrease during the disease. Do not let the patient drink from a transparent glass, but put the drinks into a colored cup, which distincts from the color of the table on which it stands.



A transparent glass looks similar to the surrounding area and people with dementia, over time, can no longer see it. The patient's plate should also distinct itself in shape and color from the table. For example: do not put a white/beige plate on a white tablecloth. The best plate to use is a plate of which the edge is colored/painted, like a clear demarcation. This prevents tampering. If the edge is not visible, the patient will shove the food on the tablecloth.



Car

Stepping into the car became more and more difficult for my wife. The interior and mats were black and she did not dare to step into this 'black hole'. I put down a white cloth on the mat in the car and now she tries to put her feet on this cloth and the problem is solved. This is an example of a small and cheap solution for an important problem in daily life.

Causes of unrest, panic, anxiety

We must realize that unrest/deviant behavior usually has a cause and is not typical for Alzheimer's or something that belongs to dementia. We have noticed that proper ventilation has great influence. That's why we pay extra attention to this subject.

It appears that a patient in eg. a room full of people can be very sensitive to an excess of carbon dioxide = CO₂ (the volatile compound we breathe out) On our motor boat I noticed that my wife at the end of the night became agitated, anxious and panicked. She had to get out of the boat. I thought this was a new and nasty phase of the disease. A tranquilizer tablet made it possible for her to calm down again.

I expected that this would happen soon again and also at home, but it didn't. But then the weather conditions changed, it became bleak and cold. Usually I left our bedroom window slightly open at night, but because it was too cold, I closed the window. At the end of the night my wife became anxiously and started to panic. It was terrible to see this. My thoughts went back to the same behavior she had during that one night at our boat. I also remembered a story from my doctor about what could happen in case of excess of CO₂: short respiratory arrests and the reaction of the body to this with unrest, convulsions, apnea etc. Conclusion: the closed window in the bedroom, as well as the "limited space" in the boat resulted in a slight oxygen deficiency and an excess of carbon dioxide (CO₂). I therefore opened the window and in a short period of time my wife's 'troubles' stopped. In many joint rooms, we see the same problem.



It was very instructive to experience from such a close distance that, despite of the progress of the dementia process, we are still able for a long time to respond to problems that occur. Our insulation urge causes the CO₂ level to be 2 to 7 times higher inside than outside. Outside we measure 400ppm and inside our insulated buildings measurements are 700 - 3000ppm. For many people, both young and old, this can lead to serious disturbances in the brain. The maximum statutory standard is 1200 ppm. This is almost never measured or controlled, but is a dangerous assassin.

Ventilation

I want to pay extra attention to this topic, because it has a huge impact on the behavior of the patient, both day and night. In practice, we close the doors and windows to sit down warm and cozy and we do not want a draughty room.

However, patients are very sensitive for the excess of CO₂ and without knowing or measuring, we can bring them in big trouble. It often causes anxiety, panic, aggression, etc. which we then very

often try to suppress with medication. The eventual consequences are incontinence (peeing and pooping in pants), etc. etc. We do measure the temperature in almost every room, but do not measure our "exhausts".

There is much interest in CO2 emissions worldwide related to the icecaps and sustainability of our natural environment. But in our homes, where the CO2 value is 2 to 7 times higher than the value outside, we are sleeping and may bring patients in big trouble. This excess of CO2 undoubtedly accelerates the dementia process and may be a major factor and/or co-responsible for the emergence of this.

Sufficient oxygen instead of CO2 is essential for our brains. Attention Deficit disorder, snoring and apnea are also examples, which can be connected to a lack of ventilation (oxygen) and an excess of CO2.

Please find below a picture of a CO2 measuring device.



Climate Control

Some construction projects applied climate control and sometimes CO2 measurement is also present. Above a value of 800 ppm problems may occur in patients. Outside, the air contains 400 ppm CO2. Inside, a value of 600 – 1000 ppm is desired, 1200 ppm at the most. However, values between 1000 ppm and 3000 ppm are common, sadly enough.

So, extra attention is needed for joint rooms, where several people are staying, especially in nursing homes. The CO2 value can quickly increase here. Also in bedrooms, the CO2 increases fast

(= within 30 minutes) in the absence of ventilation. CO2 measurement is urgently needed for the patients.



Ventilation can be done in many ways. If we want to save energy, then there are many systems where the fresh air is heated by the drained warm CO2 air from the house. In many older houses the solutions might be grates and/or opening a window. There are also quiet little wall fans, which are adjustable in speed and they ensure a steady supply and prevent a draughty room.

But still a slightly draughty room is needed. A grate or an open window can be enough.



Finally

There still is much more to tell and write about this subject but I will stop now. For all those who do not have a computer or do not know how to handle it to search for information on Alzheimer's dementia, they can read about a lot of experiences in this guide, from which they hopefully can benefit. I hope it will make it a bit easier for patients and caregivers to cope with this disease. It always is sad when dementia is diagnosed, but please try to provide yourself with some relief by reading this booklet and trying the advices at home.

My wife and I enjoy life and have thoroughly enjoyed each other, and our children and grandchildren, family and acquaintances. Sometimes we found things out the hard way, but these experiences contributed to the fact that we still have a lot of fun. Although the world surrounding you is getting smaller, because of the dementia. For all who are able to deal with the computer I would like to refer to the larger Alzheimer organizations or please consult your case managers.

On the next pages you will find a summary of points of attention and persons, you will bump into or get engaged with sooner or later. Please read it through and see what, when and how this is applicable for you. If you have questions, please contact your case manager. You will encounter a number of things we have already treated extensively in the chapters in this guide.

Examples of relational interest

1. Ascertain deviant behavior / actions. When do we talk about a bad feeling?
2. Who raises the subject?
3. How do you bring the message?
4. How to deal with denial? (Thinking: Everyone has his or her own troubles)
5. How to deal with impairments? No discussions? Extra control?

The patient continuously challenges you to mention the things that is going wrong. Patients with dementia keep asking how they are doing and do not want to hear they are not doing well enough. Do we confirm this or not? The relationship sometimes gets under considerable pressure because of the aforementioned points. Caregivers really must convert the button fully and keep in mind that the patient is the one who is always right and does not do anything wrong. Meanwhile, we may try to correct unobtrusively in our talking and actions. Always start with mentioning the good part and then mention the 'but....' Because the first signal is received as a 'good' signal, the correction may be perceived by the patient as less annoying.

6. If there is no danger, then do not help and correct patients too fast. Just let them go their own way, even though it really touches you emotionally. Sometimes its really sad to see how someone is struggling with daily actions. But it is very annoying for the patient if you help them right away.
7. When and why can the patients no longer do certain things on their own? Who will guide and correct them? Critical areas: toileting, washing, dressing, driving, cycling and other transport. Orientation problems are: walking, shopping and getting lost in your own home.
8. How to deal with intimacy? Can we adapt and how? Adherence and cuddling can increase.
9. How to deal with possible aggression? Patients can become aggressive.
10. How can we prevent sorrow and possible aggression? Do not discuss with the patient. Correct unobtrusively. Appreciate what they still can do and also let them know you appreciate this. Prevent failure or fear of failure. Remember that any help/guidance/care we provide (how well intentioned) can make the patient sad or aggressive. Also in tests at the GPs, hospitals and day care, we should realize that we should not assist/correct or ask the patient do it again, this can give them annoying feelings.

11. When can we talk about the patient and the disease, while he/she is still present in the room or should we wait until they are out of the room?
12. When and what subjects do we need to discuss in presence of the patient, regardless of the emotional consequences? The possible development and consequences of commencement. Permissions. Legal aspects. Farewell.
13. Remember that sometimes the one who is closest to the patient often is seen as the bogeyman. He/she usually is the bearer of "bad message " regarding for example more drugs, visits to doctor, moving to a nursing home etc. etc. Emotionally, this is very hard and it brings many sad moments.
14. If you have strong connection with the patient, borders can fade easily. This should not happen at the expense of the caregiver. Hence you should evaluate periodically from one caregiver to another. A case manager can also take the initiative here.
15. The rithm of day and night can sometimes be severely disrupted. Agitation, convulsions and respiratory interruption in the night can be the result if for example the patient has to go to the toilet, but they do not go or tell it themselves. When I take my wife to the toilet in the middle of the night, it gives us the rest we need. The cause can also be found in poor ventilation, thus too little oxygen in a room and an excess of carbon dioxide (CO₂), which we constantly exhale and is odorless (for example the bedroom, room where several people are together).

Communication lines

Medical communication lines

General practitioner
 Geriatrician
 Neurologist
 Pharmacy
 Rehabilitation specialist
 Psychologist
 Occupational therapist
 Family care support center
 Dentist
 Home care organisations
 Daytime Activities
 Health care institutions

Communication and approach to neighbors

Husband/wife/partner
 Children/grandchildren
 Family (parents, brothers, sisters etc.)
 Peer support
 Nearest neighbors and acquaintances.
 Caregivers
 Social network (employer, shops, church, associations)

Others

Bank
 Notary
 Other legal steps
 Media

Important to know is that you can run into a huge bureaucracy at some organisations. Hence, you have to ask for one contact person when contacting these organisations, and carefully write down this person's name and contact data. This way these organisations cannot give the problem to the next person in the row.

My advice would be to keep in **control**, also within your relationship with family, despite the intense emotional effect.

Do not let the wide range of services offered by the healthcare world suck you into the system, but make choices that meet up to your specific circumstances, in consultation with your loved ones and possibly a case manager.