

Longer me. *Longer one family.*



Think ahead *and take control!*



Alzheimer's – *and now?*

Alzheimer's disease changes the entire life – both, the person affected and their family. But there is a whole range of help available to enable you as the caring relative to cope more easily with the tasks you will have to perform. One of the most important aspects is good information. Knowing what you actually have to deal with: how Alzheimer's disease is manifested and how this illness changes the person close to you.



Alzheimer's disease profile

A question of age or not?

The cause of the mental decline is not age because Alzheimer's disease is not a symptom of age. However this illness typically affects the elderly: the risk of getting the disease increases with age. From the age of 60 the risk doubles every five years. Therefore between 80 and 90 the risk of being affected is quite high.

Dementia = Alzheimer's disease?

Dementia does not always mean Alzheimer's disease. The term 'dementia' is used to describe a condition that is characterized by loss of mental function which affects daily activities. Alzheimer's disease is the most common cause of dementia. It is diagnosed in a substantial number of cases of all dementia patients.

Slow but persistent

In Alzheimer's disease nerve cells die in certain areas of the brain – but not overnight. The onset of the disease tends to be gradual and initially goes unnoticed with mild lapses of memory. Progressively mental capacity and consequently independence is lost.

Mild stage

Mild mental deficits such as lapses of memory or problems with time orientation may occur. Living independently is usually still possible.

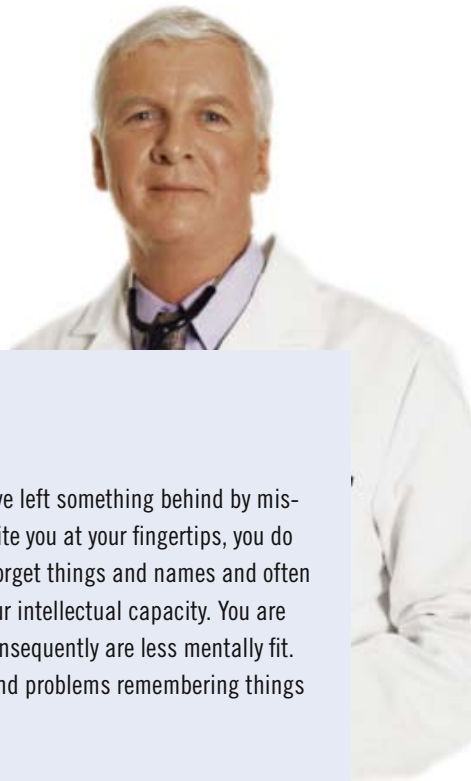
Moderate stage

The loss of intellectual function increases. Orientation capacity is noticeably lost, loss of memory and problems with speech and recognition become more apparent. Body care is increasingly neglected, the ability to reason and solve problems also disappears along with the ability to carry out daily activities. Sometimes additionally to this occur delusions, for example the strong conviction of having had something stolen.



Severe stage

The ability to perform daily activities is completely lost – the person affected is fully dependent on the care of others. Memory and speech have disintegrated, orientation is lost: it is hardly possible to form sentences any more and events in the past can no longer be recalled. Even trusted people are no longer recognised. Bowel and bladder control is lost.



Is that still “normal“?

It does not always mean Alzheimer's disease ... if you have left something behind by mistake and forget or do not have the name of the person opposite you at your fingertips, you do not need to worry for a long time yet. Even if you frequently forget things and names and often can't concentrate, you do not need to be concerned about your intellectual capacity. You are more likely to be suffering from stress at the moment and consequently are less mentally fit. However, the difference between pathological memory loss and problems remembering things is narrow.

For your guidance:

Indicators of normal memory loss related to age are that symptoms occur only in those over 60, they are only transient and occur occasionally. Intensive deliberation and concentration leads to recall of the thing forgotten or the misplaced object. Also events are not completely forgotten, just some details of them.

If symptoms such as memory loss are present earlier than the age of 60, are persistent and even become progressively worse over months, the alarm bells should ring. This could be a case of dementia. Characteristic symptoms are increasing memory loss: names, dates, telephone numbers can no longer be readily recalled, appointments are missed, objects misplaced. What is known as cognitive functions – ability to think and learn, reasoning and judgement capacity, calculation, orientation and speech – are increasingly lost. Other signs of deteriorating brain function are disturbances in concentration and attention. These are joined by increased irritability, lack of drive and rejection of social contacts. The main indicator of dementia is that whole memory contents are completely forgotten and despite intensive deliberation can no longer be recalled.

Alzheimer's Alarm?

As already stated: Alzheimer's disease does not appear out of the blue, but develops over years. So some things that appear “humorous” to the outside world may already be the first sign. These alarm signals should be reasons to discuss your concerns with a doctor, especially if there is a noticeable change, also noticed by family members and friends:

- increasing memory loss and inexplicable states of confusion
- difficulties carrying out everyday tasks
- language problems and problems finding the right words
- disorientation in space and time
- impaired judgement, such as wearing inappropriate clothes
- placing objects in odd places, e.g. spectacles in the refrigerator
- pronounced mood changes and changes in behaviour
- marked personality change
- loss of own initiative and motivation
- impairment to make decisions

There is a lot to do ...

➤ Unfortunately Alzheimer's disease is not yet curable. But in the meantime there are some effective strategies for slowing down the mental decline. These include mainly specific drugs, generally known as antidementia drugs. These medicines can delay the disease progression and improve the symptoms: the brain's performance and the capacity to carry out everyday activities are thus retained for longer. Two groups of drugs are now available for positively influencing the nerve messengers glutamate and acetylcholine: the active substance memantine reduces the damaging effects of glutamate by docking onto the relevant nerve cell receptor. Learning signals can then be recognised again, patients become more mentally active, everyday competence is improved. Patients who need care also benefit: they are more mobile, are able to maintain their personal hygiene better, dress themselves, recognise people again, are better able to understand the content of a conversation and also respond better. This all reduces the care time enormously – by more than 50 caring hours per month. Initial clinical evidence indicates that memantine could even prevent nerve cells from dying.

The second group of drugs are acetylcholinesterase inhibitors to which the active substances donepezil, rivastigmine and galantamine belong. They reduce the breakdown of acetylcholine already produced by the brain. If this messenger is available for longer, the transmission of information in the brain is improved.



Why me?

Alzheimer's disease can affect anyone of us. It is therefore not a question of "Why" but rather of "How". What causes the death of brain cells has still not been fully clarified. However, it is now clear that during the course of the disease more proteins, generally known as amyloids are increasingly deposited in the brain. This prevents the information flow between the nerve cells: in Alzheimer's disease the interaction between the nerve cells is disturbed because there are too many or too few messengers, such as primarily glutamate and acetylcholine. These neurotransmitters are essential to all intellectual processes. A deficiency or excess of these messenger substances can cause nerve cells to lose their ability to function and they die. The more nerve cells that die the more marked the mental and everyday deficits will be. Drugs can act in a targeted way in these pathological processes – and as a consequence the symptoms of Alzheimer's dementia improve and the disease progression is slowed down.

Remain *active*

➤ In the first place Alzheimer's patients need love, understanding and acceptance. Their familiar world is continuously disappearing and from this uncertainty, mistrust becomes ever stronger. Thinking, feeling and experiencing – everything is marked by fears of loss and increasing inner loneliness. To avoid painful experiences and not to be constantly aware of new weaknesses in themselves, those affected frequently revert to inactivity and become indifferent. In this way they cannot make any mistakes and cannot blame themselves . . . Understandable of course, but not good.

It is much better for Alzheimer's patients to be mentally and physically challenged according to their likes and capabilities. Gentle activation brings rewards in many regards and above all: it is easier than you think. Many abilities are retained for a long time, such as for example the sense of rhythm and movement. Music generally gives patients a lot of pleasure – what about singing together or perhaps a little dance as well?

Such suggestions are usually readily accepted. After all they promote strengths and abilities that are still present. Nothing is nicer for an Alzheimer's patient than finally still being "able to do something". Sometimes these type of activities bring previously undiscovered abilities to the fore.

In principle the following also applies: remain active for as long as it's possible. Encourage the person to continue his/her hobbies, help him/her to maintain his/her social contacts and create specific mental stimulation for him/her. To maintain the mental as well as the physical activity for as long as possible physiotherapy (mobility therapy) and activating exercises such as walking, hiking, swimming or dancing are a good idea.



The good feeling of being needed

☞ Polishing the silver, weeding, doing the washing or dusting ... in every household and not only there, there are many tasks that Alzheimer's patients can do – which almost without exception they are grateful and pleased to do. Ultimately these tasks communicate to them that they are useful and needed. The occupation that you suggest in your particular case depends on the patient's state of health and of course on what he/she used to like doing. But it doesn't matter what it is: the vitally important thing is that active participation in everyday activities gives the patient's life more meaning.

In addition to jobs around the house and garden all activities that awaken memories are to be recommended. These include primarily looking through photograph albums, as this quite clearly creates a connection with the past. If the patient liked travelling, looking at films will certainly also bring him pleasure.

Also shopping and window shopping, chatting over a coffee and simple board or card games will be a pleasant experience for the patient. And this is what it is all about: promoting positive experiences. At last a break from the daily frustration of lost capabilities ...



Alone among strangers

When dealing with dementia patients it helps enormously to try constantly to put oneself in his/her position in order to understand his/her inner needs. Imagine for example that you are placed utterly alone in a village in Central Africa, where you do not know anybody and do not understand anybody.

Everywhere you come across incomprehensible customs and unknown objects. The worst thing is that you constantly meet people who talk to you and act as if they have known you for a long time and expect you to know all about everything. How would you feel?

Alzheimer's etiquette

Anyone who has to do with dementia patients on a daily basis must observe some social etiquette. The prime necessity is to remain patient, friendly and understanding – even if this is sometimes very difficult.

- ☞ Try to adopt a caring but at the same time definite and clear manner of speaking.
- ☞ Be patient with the patient and give him time (minutes, not just seconds) for a reaction or response.
- ☞ Give clear instructions in simple, short sentences and speak slowly and clearly.
- ☞ Repeat important information as needed, if necessary several times.
- ☞ People with dementia react less to the content of what is said and more to the feeling of how it is said – more “how”

than “what”. Therefore please make sure that what you say is what you mean and is in keeping with your facial expression and body language. Ambiguities are recognised quickly by Alzheimer's patients and they are very hurt by them.

- ☞ Try to ignore accusations or reproaches: do not engage in nonsensical discussions. Instead of maintaining your own opinion, it is better to adopt a conciliatory stance.



- 👉 Praise is better than criticism – you can do this by smiling or a caress.
- 👉 If there is still anger: please keep telling yourself that Alzheimer's patients have lost at least partial control over their behaviour. Even if it sometimes seems that the patient affected is simply being obstinate and unwilling to comply.
- 👉 Ensure that there is stability and routine in daily activities: simple rules and fixed habits are a lifeline for dementia patients.
- 👉 And finally the most important point: always remember that any form of emotional attention is like medicine for the person you are caring for.

Keep your brain fit

👉 Poor condition of the grey cells is often behind deteriorating intellectual performance. Like any muscle the brain's fitness must also be trained.

To keep the grey cells fit brain researchers recommend, in addition to specific memory exercises, adequate exercise and a healthy diet.

Food for the grey cells

To maintain performance the brain must be supplied adequately and correctly. As research shows, certain nutrients are extremely important for mental vitality – additionally to drugs and physical activity. Impaired brain function is often caused by a deficiency of minerals, vitamins or other substances.

The most important nutrients for keeping the grey cells fit for longer and performing well are:

- 👉 Vitamin B1
- 👉 Vitamin B3
- 👉 Vitamin B6
- 👉 Vitamin B12
- 👉 Folic acid
- 👉 Antioxidants

They protect the brain cells from damage by free radicals. The connection to Alzheimer's disease has been scientifically proven: an adequate supply of antioxidants can reduce in a lasting way the risk of Alzheimer's disease – by up to 19 percent. The best are vitamin C, vitamin E, beta-carotene, selenium, coenzyme Q10 and alpha lipoic acid.

- 👉 Essential fatty acids: omega-3 fish oil (DHA and EPA)
- 👉 Aminoacids such as lecithin, glutamine, lysine, tryptophan and tyrosine





Brain jogging: exercise also keeps us mentally fit

It is known that people with dementia usually have a marked urge to move. The constant wandering and moving about is often problematic as the patients can easily endanger themselves and others. The urge to wander can however be utilised constructively for regular exercise. On the one hand exercise lifts the mood as it promotes the release of what is known as happy hormones, the endorphins. On the other hand mental fitness increases along with physical fitness: if as a result of increased muscular activity more blood is pumped through the blood vessels, blood and oxygen supply to the brain is intensified. This raises the performance of the brain by on average 13 to 20 percent. In addition exercise, especially gymnastic exercises such as yoga, stimulates the motor and sensory nervous system to form new neuronal contact points. The network of individual nerve cells becomes more closely linked and more neurotransmitters are produced.

Not least regular exercise allows life to tick by more slowly. Sport, science tells us, cannot stop the ageing process but can slow it

down. Regular moderate exercise acts like a fountain of youth on the body. It reacts to this with increased oxygen consumption, blood supply to the cells and tissue improves and as a consequence they are supplied with more nutrients. In addition regular exercise allows a high level of antioxidants to be produced quickly in the body.

Brain researchers advise Alzheimer's patients to engage in endurance sports: jogging, cycling and swimming. Gymnastics and yoga exercises also help to retain coordination and concentration capacity for longer.

Brain teaser

Learning by heart, learning a language and reading, also playing chess, solving cross-words and thinking tasks are suitable for brain training. Here is a sample:

Training for the grey cells

Memorise the following numbers and write them down by heart:

040/465 33 36 14.6.1994 67,840

Hide now the numbers and look in each of the following column of figures for the right one:

040/456 33 36	14.6.1994	67,480
040/465 36 33	14.7.1994	76,840
040/465 33 36	13.6.1994	67,840
040/456 36 33	13.7.1994	76,480

Memory outpatients

In many of the larger towns and cities there are now units that specialise in the diagnosis and treatment of dementia – known as memory consultations, memory outpatients or memory clinics. Neurologists, psychiatrists, specialists in internal medicine and the treatment of elderly patients and/or neuropsychologists work here, in order to clarify the precise cause of the memory deficit.

The team summarises the individual results in a “diagnosis conference”. The doctor providing treatment explains the diagnosis in a detailed consultation with the patient and his/her family and discusses the treatment possibilities. Many of these units also offer self-help groups for family members.

Living *with the disease*

It is not just in dealing with the patient that there is a lot to consider. Also in everyday activities a lot has to be changed with the diagnosis of Alzheimer's disease. This does not mean that the house or apartment has to be completely converted all at once. On the contrary, too many changes to the familiar environment trouble and irritate the patient unnecessarily. To make the patient feel secure, generally the well-known minor details are sufficient, such as for example labels, grips, good incontinence pads or special drinking cup.



Day after Day

The more the dementia progresses the more dangers lie in wait for the patient - especially in the home environment. Potential risks must therefore be avoided and removed as far as possible.

- Carpets and runners that are not attached to the floor should be removed. There is a danger that the patient will slip or trip over them.
- Ensure that there is good adequate bright lighting in the rooms.
- Glass panels in doors should be clearly marked, perhaps with stickers.

- You should "smooth" sharp edges on pieces of furniture: in specialist shops you can buy protective pads.
- Breakable glass or vases should be kept in a safe place.
- Make stairs, windows and balconies secure so that the patient cannot fall.
- Fit child protective devices to cookers and boilers. Also store electrical devices such as bread cutters or toasters out of reach.
- Do not leave any lighters or matches lying around.
- If the patient smokes, he/she must only do so when someone else is present to reduce the risk of a fire.
- Under no circumstances should keys, especially car keys, be left lying around.
- Hang a curtain in front of the front door so that this is not seen as an exit. This reduces the risk of the patient wandering off.
- Remove poisonous plants and any with spines, such as cacti.
- Do not leave any medicines lying around where they can be accessed. You should also always lock away any household chemicals.

- Obtain clothing that is easy to put on, comfortable and easy to wash. But with all their functionality the patient should also like them. The practical requirements should not be the dominant factor.
- Anti-slip and comfortable shoes that provide good support are also important. Velcro fasteners are ideal, especially in the later stage of the disease.



Hygiene

- Try to keep taking a shower or bath always at the same time of day.
 - Shower seats, bath aids and grips should be used for showering and bathing. Especially important are anti-slip mats – you can find all of these items in a medical supply shop.
 - Try to make bathing or showering pleasurable: with relaxing music, pleasant fragrances, soft and cosy towels and perhaps even candles. Like a small celebration that the patient and you can enjoy.
- Alzheimer's patients forget certain movements. Brushing the teeth, shaving or doing the hair can be a problem. Show the patient how these are done. He/she will try to copy you and recall the movements once so familiar.
 - Gentle and rhythmical brushing or combing of the hair are a welcome treat – not only for the Alzheimer's patient ...



Dinner is served

Daily mealtimes are often the only pleasure that the patient still has. If the patient is allowed and can help – laying the table and clearing up, lending a hand with the cooking – the feeling of belonging and of purpose is even greater. It can be problematic when the disease progresses. Then either too much is eaten because the last mealtime has been forgotten, or too little. The latter is far more common. A deficient diet is commonplace in dementia. Food does not taste of anything, somehow the patient does not know anymore what eating is and how to use the cutlery ...

Happily today many helpful utensils are available to make caring easier. For example at mealtimes non-slip plates and spoons, also large handles and cups with spouts. Perhaps this does not look so nice but they are a great help. For you and also for the person you are caring for ...



Here are a few eating tips appropriate for dementia.

- Make sure that the atmosphere is calm and relaxed while eating.
- Keep to fixed mealtimes.
- Serve small meals often during the day. Several courses and intricate dishes are not good.
- Put simple and well-known meals on the table, also not too many different foods at the same time.
- Spice intensively: a strong taste stimulates the appetite. Often sweetening helps too, also hearty dishes are more pleasing to the patient.
- Make sure that the patient has enough to drink. The rule of thumb is 1.5 litres a day. Place carafes with water and a glass in several locations in the house – this reminds them to drink.

- Thicken drinks, for example milk with yoghurt or pudding powder. This makes drinking easier as dementia patients can easily choke.
- Many Alzheimer's patients prefer to eat with their fingers. "Finger food" is liked ... in general the dishes should be easy to get hold of or soft enough to use a fork.
- Hard foods such as nuts or crunchy foods are less suitable. By contrast sweet dishes with a soft consistency are very popular.
- Help if needed during eating: for example guide the patient's hand when cutting or using a spoon. Often this will lead to recall of the movement processes.
- When feeding remember that instructions to swallow and chew may possibly no longer be understood.
- Food and drinks should not be too hot as there is a danger of scolding, often not recognised by dementia patients.

- Clear contrasts between the tablecloth, plates and food are important. A light-coloured soup in a white cup on a white tablecloth will not be seen easily.
- The table should be laid for everyone, also for you as the carer. Otherwise the patient may have the impression that he/she has to wait as not everyone has something, or that the others have already finished.



Do not forget *yourself*



Looking after an Alzheimer's patient is enormously strenuous: a 24-hour job, in which many carers overextend themselves each day. Constantly in conflict between love and a sense of duty, a sense of responsibility and exhaustion, despair and a guilty conscience. It is therefore important that you learn to develop a healthy egoism – as self-protection that you urgently need. It is essential that you think about yourself. The task that you have to perform also requires equilibrium and respite. Regular breaks in which you can relax and think about yourself for once are therefore essential. Otherwise you take the risk that at some time there will be two patients: the Alzheimer's patient and you as a totally overburdened caregiver.

Do not let yourself become ill

You too as a family caregiver need support. The great physical and mental input, the interferences and financial sacrifices, the social exclusion and the inadequate opportunities to recuperate – all of this is an enormous burden which is often underestimated. Sometimes with fatal consequences. Anyone who is subject to both physical and above all mental strain, day in and day out, is therefore at risk. Not without good reason many caregivers become ill themselves – the price for years of being overburdened and stressed 24 hours a day. You must and should not pay this price. Remember the following – not only in your own interest but primarily for the well-being of the patient. He/she will not derive any benefit from you if you are totally spent and break down under the strain of the task you have to perform.

You are "only" human – share your duties

Every caregiver must recognise that he/she has his/her limits. It is extremely important not to exceed these all the time but to be very careful to keep within them. Respect the fact that you cannot be perfect – nobody is – and allow yourself to be human. This may

sound strange. But many family caregivers demand achievements of themselves that are far beyond the limits of what is possible for them.

Take warning signals seriously

Anyone having to worry about another person round the clock quickly forgets himself. He/she loses sight of his/her own needs and above all does not pay attention to the signals that his/her body and soul are sending: only when the limits have been reached and perhaps even exceeded. You should not allow it to get that far. Pay attention to the signs that are being sent to you. This does not happen for no reason and consequently it is essential that you respond as quickly as possible.

It's ok to vent your feelings

This happens to everyone who cares for an Alzheimer's patient: sometime patience just snaps. You become furious, shout at the patient and reproach him. Afterwards the nerves are even more frayed. How could you be so unfair... wrong. It is completely under-

standable that you have to vent your feelings at some point. No one can live constantly under stress and always endure behaviour that would not be tolerated in healthy people. Instead of reproaching yourself for the outburst it is much better for you to learn from this situation: it is a clear signal that you have reached the limits of your endurance. This means that you must take a step back and have a break.

Caution frustration

You no longer have any prospects for yourself? You view your future prospects only negatively? You are often in a bad mood and depressed? Then the alarm bells should ring in fact loudly. You should take these signals absolutely seriously and regard them as a trigger to visit the doctor.

Leisure time is obligatory

This is quite clearly part of your job: leisure time, regularly and on time. Best of all a whole day and one night a week. It is important that this is the opposite of your normal daily activities – this will bring the most



relaxation. In practice this means: exercise in the fresh air, contact with nature, demanding conversation, going out and doing something, meeting a lot of people and keeping in touch.

Having time off also of course means that you must have another temporary caregiver for the patient. Essential for you to refuel with energy again and primarily also enjoy life and finally to be able to relax. For this to work you usually have to take the initiative yourself and ask for help in your immediate circle: in your own family or group of friends, as social welfare units and day clinics rarely have staff available. And not trained people on whom you can rely with a clear conscience. A family group is ideal in which the members help each other out.

Relaxation is doubly worth while

If you take regular breaks and relax quite specifically, this benefits both you and the patient greatly. What really relaxes you you may have possibly discovered already – but this is not so easy. Relaxation techniques are very helpful and established, in particular autogenic training. This allows deep and lasting relaxation within a few minutes. Afterwards you are fresh again and recuperated. The technique of autogenic training is best learnt with specialist instruction and experienced teachers.

Self-help

A delicate subject ... for it is sad but true: professional helpers, especially if needed at short notice are difficult to obtain. If there is an acute need for a caregiver at short notice, far too often this is a problem. For this reason contacts with self-help groups are very important and helpful. To find out about the self-help group in your area, read the details attached. If there isn't an organisation in your area you should consider starting one yourself. This is easier than you perhaps think and helps in many respects.

Exchange helps

In a member's group you will meet people in the same situation as yourself: the discovery that many other family caregivers in the group are struggling with similar problems is a great help. Talking about things is a relief, confidence and strength return. In addition the exchange brings new impulses and stimulations for dealing with the patient. And not least, meeting regularly with the group is a welcome change – a sociable break from the everyday caring activities, which brings valuable information as well as social contact.



Unfortunately there is not a member's group everywhere. A good reason to seize the initiative and start one yourself. Via your doctor – generally your GP – you can ask who is also looking after dementia patients in your area and approach these people. The response to the suggestion to form a self-help group is usually good. If you have found enough interested people (a minimum of four) the first meeting has to be arranged. It is best for this to take place at the home of one of the future group members. If this is not possible for anyone there may be a possibility of meeting in a public room in the community (church, sports club etc.).

At the first meeting you should clarify the following questions: should the group be open (that is new members can always join) or better closed? When and how often will the group

meet? Who within the group will take responsibility for what?

At the individual meetings joint discussion is the focus. Every participant should be able to bring in what is troubling him/her and what he/she needs advice and support for. This also means that a member can definitely ask the others for care of his/her ill relative from time to time. This aspect of reciprocal help also at short notice is an important element of such a group. By helping others to solve their problems you are helping yourself.

Here you will get help

📌 In the meantime a number of opportunities for the care of dementia patients and their family caregivers have become established. These vary according to region and have advantages and disadvantages.

Advice from Alzheimer's Societies

Alzheimer's advice centres offer information free-of-charge on all questions concerning supplies and care, and of course on legal and financial aspects. There is usually also psychosocial counselling and more long-term support.

Family groups

A valuable and very beneficial way to offload. The focus is on help towards self-help of family members affected. In the groups knowledge about the disease, stimulating suggestions and advice are exchanged. In addition meeting regularly offers the opportunity for free expression of feelings in an atmosphere of interest and understanding.



Care groups

A good initiative in the outpatient sector: in care groups dementia patients are looked after on one or two afternoons each week by unpaid assistants and a specialist worker. Care groups are not available everywhere. Contact the Alzheimer's Society about opportunities in your area.

Inner circle of helpers

Once to twice a week the patients are looked after in a small group for up to three hours and occupied according to what they are still able to do. This is carried out by trained lay assistants, requires little bureaucratic input and does not cost very much.

Outpatient Care Service

Individual care tasks are taken over by outpatient care facilities for the elderly, social welfare units, domestic care associations and neighbourhood help associations. However they are generally not geared up for the special needs of dementia patients. The focus is on physical care and not much on psychological care.

Daily Care

For patients who cannot be looked after during the day but only in the evening and at the weekends. The programme covers mainly occupation in the community along with physical and mental activation. Nevertheless daily care is not directed enough towards the needs of the patients and is not very flexible in terms of time.

Respite Care

Family members can make use of this when they have to go away or are ill themselves: up to four weeks each year are usually paid for by the care insurance funds. It is important to clarify beforehand whether the facility is suitable for dementia patients. In addition it should be remembered that the stay is often problematic for the patient. For this reason many respite care facilities offer trial days to gauge the reaction of the patient beforehand. For example, patients who are likely to wander off are rarely accepted.

Holiday with Care

As an alternative to respite care a number of regional Alzheimer's Societies offer holiday with care for patients and their family. Here in addition to joint activities enough opportunity is also given for the caregivers to have free time – during which trained caregivers look after the patients.

Residential Home Care

When care at home can no longer be maintained even with additional help, the only possibility is generally to live in a protected ward where it is not possible to leave unnoticed.

Important when choosing a nursing-home

Good homes should

- protect the patient's private space
- promote his/her independence
- ensure mental activation and physical fitness
- include the family members at their request in the care and utilise their knowledge about the patient's individual likes and dislikes
- offer care structured over the day which takes into account the special needs of the dementia patient
- treat the residents in a dignified way and with respect

What you *should know*

As the disease progresses the Alzheimer's patient needs an increasing amount of help and care. But who can help and how? What do you have a legal right to? All this must be clarified early on. You are not taking this on alone: the Alzheimer's Societies are there for patients and their family caregivers with word and deed. In addition to extensive information about Alzheimer's disease you can get answers to questions about looking after the patient on a daily basis. For example in some countries there is care insurance which provides protection against the risk of requiring care in order to improve the situation of the person affected and to boost the quality of their care.

Think about the fact that sooner or later the Alzheimer's patient will no longer be able to make his/her own decisions. Consequently when the person is still comparatively "healthy" orders and powers of attorney in written form should govern what is important – ideally authenticated by a notary public.

Common legal issues

Especially in the severe stage of Alzheimer's disease there may occur legal problems. Caregivers should be aware of these things. Therefore it would be important, to consult your doctor and discuss with him legal backgrounds as early as possible.

The most important issues are listed below:

- Last will of the patient should be fixed.
- Financial aspects should not be forgotten, for example a power of attorney for the bank account.
- To make sure that the patient gets the kind of care he/she would like to have an advance directive should be written down.
- Another important issues that is very often forgotten is the driving ability of the patient. It might be the best to let it check, if possible for example at a driving school.

Who can help?

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