

ALZHEIMER
DISEASE
AT HOME



PREVENTING
CARER
EXHAUSTION



**FRANCE
ALZHEIMER**
& MALADIES APPARENTÉES

www.francealzheimer.org

THE WHOLE FAMILY OF SOMEONE WITH ALZHEIMER'S NEEDS SUPPORT



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This translation of an original Association France Alzheimer guide “La Maladie d’Alzheimer et les maladies aparentées” was created by the volunteers of **Association France Alzheimer Dordogne** www.francealzheimer.org/dordogne

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Factors such as long periods spent providing care and support with little or no time to rest, the number and variety of tasks to be done throughout the day... these challenges may explain why the physical and psychological exhaustion of being a family carer can occur. This will affect not only the carer’s ability to look after someone and maintain their quality of life, but also seriously jeopardise their own health.

It is important to highlight the difficulties of **social and emotional isolation**, time spent in an increasingly demanding relationship that requires ever more commitment from the family as well as difficulties finding the time to **meet their own needs** and the **lack of acknowledgement** received in return.

There will also be feelings of guilt when the carer has to do things without the patient’s knowledge, another factor which is responsible for feelings of exhaustion.



A COMPLEX SUPPORT RELATIONSHIP

Exhaustion of the carer is often due to a lack of co-operation and acceptance of the care being offered. The person with the disease may even strongly resist such care claiming, when still at the moderate stages, that "I don't need help". Also, caring for someone with a neurological illness can be very unrewarding since no matter what we do, problems will remain, the disease continues to develop and difficulties in communicating and maintaining relationships increase.

Accepting separation

"I felt guilty about leaving him alone and even about enjoying life's pleasures that I can no longer share with him. Guilt stifles us and prevents us from living. It's very hard for me to admit that my love can't do anything to save him from this situation..." (Mme L.)

Feelings of fatigue are universal and understandable among carers, so it is important to accept the need to take a short break.

Looking after someone who is becoming increasingly dependent makes the main carer (often the spouse) feel that they are the only person who can properly meet the patient's needs. You may then have difficulties trusting outside support such as a care professional or even another member of the family.

The need for rest and feelings of being unable to take time off will depend on

As a result: recognising our limits and taking a break is vitally important to avoid crisis situations where everything is in danger of collapsing. These rest periods, from a few hours on a regular basis to several weeks on occasion, will allow the carer to recover physically and mentally so they can continue to respond effectively to the demands placed upon them by the pressures of the disease.



the nature of the relationship with the person with the disease and his or her personal situation. Above all the carer's feelings of indispensability may make it impossible for them to envisage being apart from their loved one, even for a short break. *"Lasting the course of the disease means understanding our fatigue, our discouragement, our exhaustion. We need to put solid milestones in our lives: rely on professionals instead*

of competing with them, know how to get help, know how to delegate our powers and sometimes how to unburden our grief, to rest our heart and our backache. Some doctors help us by arranging short breaks for the patient in good care conditions". (Mme L.)

Paralysing guilt

"I can't go on like this, but I don't change a single thing about it" sums up this serious problem affecting exhausted family carers whose feelings of guilt prevent them *"even thinking about taking a break"*. The guilt can be even stronger as those with the disease may sometimes experience acute anxiety in the absence of their main carer. And this guilt can also tear out the roots of shared history. Some carers are convinced that they have to repay a "debt" (especially children). Guilt can also find us facing an unthinkable choice - our own survival at the expense of our ailing relative, hence the importance of appropriate care during the carer's absence.

It is therefore important that the rest periods carers should and must give themselves do not result in a lower standard of care for the patient. Hence the need for respite arrangements (day-care, temporary accommodation), which offer specific and appropriate patient care.

Conclusion: carers fulfil many roles for their loved ones. Too many perhaps? In the end, almost half of carers suffer significant psychological or physical problems in the course of caring for their ailing relative, even after the patient has been admitted to a care home.

Anxiety, stress, depression, changes in their personal life, reduced leisure activities and the risk of financial hardship are direct consequences of the exhausting demands on them as carers and that society imposes on them. The consequences of the lack of rest are many and serious.

Two types of leave schemes for family carers

- **Carers' Leave** This allows salaried employees to take time out from their profession or job for a period of up to three months to care for a dependent and may be split up into separate periods. This time away from work is at the carer's expense. It is not remunerated through any state service.
- **Family Solidarity Leave** This allows salaried employees to help a relative suffering from a potentially life-threatening disease or in the advanced or terminal phase of a serious and incurable illness. It covers a period of three months and is renewable once. Again there is no state financial support paid, but a daily allowance may be provided by Social Security for twenty one days (for information contact your local office of CPAM).



THE CHOICES AVAILABLE

The aim of care and respite services available is to give family carers the opportunity to let them “breathe” with the help of professional support. They should be thought of as services that provide all-round care of the patient: where, at the same time as relieving the main carer, they can also afford effective therapeutic treatment for the those with the disease.

These services cover a range of different options and although the people admitted are usually elderly, some patients under the age of 60 may also benefit.

The Specialist Alzheimer Team (ESA – L’Equipe Spécialisée Alzheimer)

Specialist Alzheimer’s Teams (ESA) have been set up within home nursing services (Services de Soins Infirmiers à Domicile - SSIAD) and bring together geriatric care assistants and psychomotor and occupational therapists. The teams visit at home by prescription of the doctor (a maximum of 15 sessions per person per year) and provide companionship and rehabilitation sessions for people suffering from Alzheimer’s or a related disease who have received a diagnosis. Mainly

aimed at patients in the early and moderate stages, these services are covered 100% by the Social Security.

The ESA has two objectives:

- To try and increase the patient’s participation in everyday activities and to preserve and/or stimulate their cognitive, motor, sensory and communication abilities.
- For the carer to help to recognise the value of their role and position and encourage and support them.

Day Care Centres



Day care centres offer admissions to those living at home who are suffering from Alzheimer’s or a related disease to an independent care home or Establishment for Dependent Elderly People (Établissement pour Personnes Âgées Dépendantes - EHPAD), for a period from half a day to several

days a week on an occasional basis. The admissions are supervised by professionals, helping patients to maintain social links, stimulating them through targeted therapeutic activities aimed at slowing the effects of the illness (cognitive stimulation, gentle gymnastics, cookery workshops, art therapy etc.). They also afford respite for close family by offering them periods to recover and take care of themselves, so they can then function

more effectively. These admissions help promote caring in the home in the best conditions possible. Financial support for day care may form part of an assistance plan as part of the Allocation Personnalisée à l’Autonomie à domicile (APA – personalised care allowance).

The lists for contact details of day care centre are available from the Conseil Général of your Département and on the website www.pour-les-personnes-agees.gov.fr

Temporary accommodation

Temporary accommodation is offered by the EHPAD run care facilities. It has several objectives: providing a transition period after hospitalisation of a patient before they return home; caring for a patient while their main carer is in hospital themselves; preparing them for a possible admission to a care home or allowing family members to go on holiday. The care may, depending on each case, be partly funded by the APA as part of a personalised action plan (for CRAM nationals – those with pension rights in France) or may be

eligible for exceptional support from certain pension funds or Conseil Général of your Département where the family lives. These admissions are subject to the submission of an application after contacting the establishment directly. However, as its name clearly implies, temporary accommodation is time limited, from a few days to a maximum of three months. It must be prepared for in advance so that the patient fully understands that it is for a limited period.

Support and respite service

The support and respite service is a recent initiative, still in development nationwide. Backed up by day care, the service offers companionship to those with the disease, support and respite to the carer and activities for the patient-carer partnership. The aim of this service is to combat the carer’s exhaustion as well as the withdrawal and isolation of the patient-carer partnership.





BETTER UNDERSTANDING YOUR COMMITMENT

Carer training was set up as part of the Alzheimer Plan 2008-2012 and is free for all families supporting a family member with Alzheimer's disease or a related illness. Training is now provided by Association France Alzheimer at a national level. Lasting fourteen hours and divided into several modules, these courses aim to give carers the skills they need to understand the symptoms of the disease and provide suitable care.

This training is available nationally (given in French) and encourages skills development. It is designed to help carers recognise the role of

the family carer, letting them find solutions to problems that arise and giving a better understanding of their commitment to their ailing relative.

Finally, these training sessions encourage the sharing of experiences and creating self-help relationships between participants.



Innovative initiatives currently under development

For example, there are the Alzheimer Respite Holidays[®]. As one of Association France Alzheimer's flagship programmes for many years, they are aimed at the patient-carer partnership. These organised vacations welcome participants at holiday centres for ten days or so to enjoy some time relaxing and sharing leisure activities.

Other recent developments include night-time carers providing home visits at set hours for patients living alone at home and overnight admissions guaranteed in certain EHPADs. These overnight care initiatives are, however, still an exception.



Examples of social reintegration initiatives

Mainly organised by volunteer former family carers, these are set up to encourage conviviality, support between families and lasting relationships among participants.

and run by volunteers and trained professionals, these outings help those with the disease emerge from their isolation and provide an opportunity for leisure and cultural activities.

Notable among these initiatives are:

- Association France Alzheimer Memory Cafés[®]: aims are similar to those of the discussion groups. Organising them in cafés which are open to the public give them an additional opportunity for a "normal" social life.
- Joint accompanied outings: associations or organisations offer trips to museums, theatres and restaurants. Specially adapted





DON'T STAY ALONE

Local Associations in every département in France really are places to seek information as well as space for listening and support through shared experiences. The aim of each Association and its volunteers is to mitigate the isolation that the family carer may suffer and offer support for their needs.

On making contact with their local association families will receive information, if they so wish, about the support open to them in their role as carers, from caring exclusively at home to staying in a care facility. Association France Alzheimer's network of local associations also offer the training sessions for carers as mentioned previously, moral and psychological support as well as informative meetings about the disease.

No one person can claim solely to have all the answers or the ability to cope when faced with the illness. Local associations bring carers and families together through sharing personal experiences, to foster appropriate ways to care in the long term, while recognising the patient's care needs, their wishes and need for dignity.

Through their sympathetic listening and because they are the "peers" of these spouses or children who come seeking information, advice or an intimate understanding of their problems, volunteers are able to

offer relatives the reality of no longer feeling alone in their daily difficulties.

But the mission of volunteers goes well beyond the scope of listening and advising. Within the network of associations volunteers enlist the support of professionals, including psychologists, to offer discussion groups for families, memory workshops for those with the disease and France Alzheimer Memory Cafés® and Halte Relais® breaks. All this is free to members of Association France Alzheimer. Volunteers also take part in the development of independent therapeutic day-care activities.

Local associations are also mouthpieces for feedback from families to help professionals learn more about their problems and needs. This feedback enables better understanding, so that when these professionals arrive in the intimacy of family homes they can provide the best support.

Find the contact information for Association France Alzheimer and Related Diseases closest to you on www.francealzheimer.org



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Retrouvez-nous sur:



Allo France Alzheimer:

0 800 97 20 97

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Siège social de l'Union nationale
des associations France Alzheimer
et maladies apparentées
11 rue Tronchet
75008 Paris