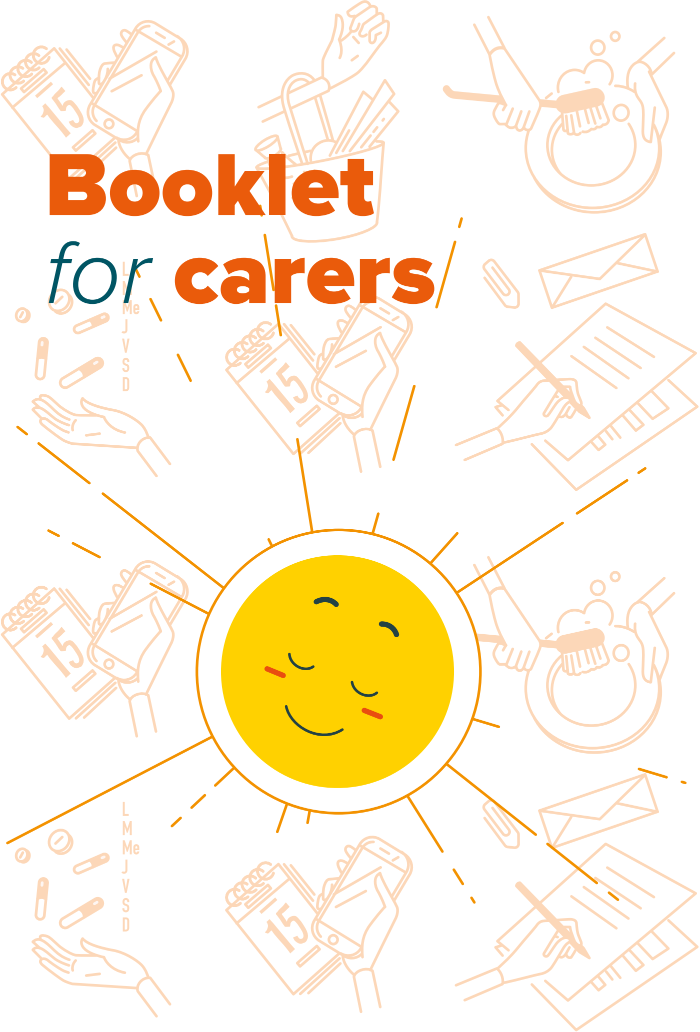
Booklet *for* carers



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A HUGE THANK YOU TO ALL THREE
FOR YOUR SUPPORT AND ADVICE!

This booklet is primarily aimed at "lay" carers.
(Rather than professionals)

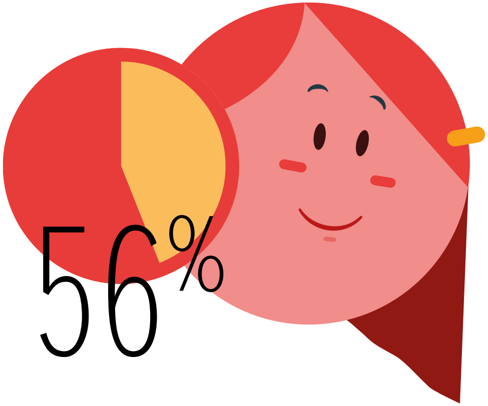
Introduction

Since the dawn of time, family members have taken care of each other. Elderly or disabled people used to live in the home and were looked after informally by those around them.

This situation has changed radically in recent decades, as families have moved further apart, women have taken work outside the home, and medical progress has made it possible to live with impairments and chronic illnesses.

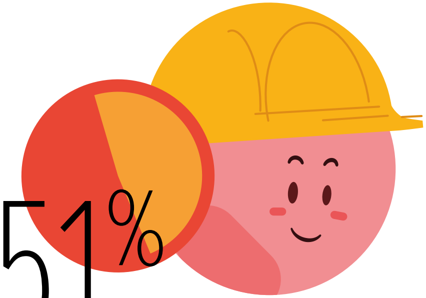
Support structures and professional home care have of course developed to address these new circumstances. However, these material solutions do not address every aspect of healthcare, and voluntary carers (usually family members) play an essential role.

IN FRANCE, THE NUMBER OF CARERS IS ESTIMATED AT BETWEEN 8 AND 11 MILLION, DEPENDING ON THE SOURCE.



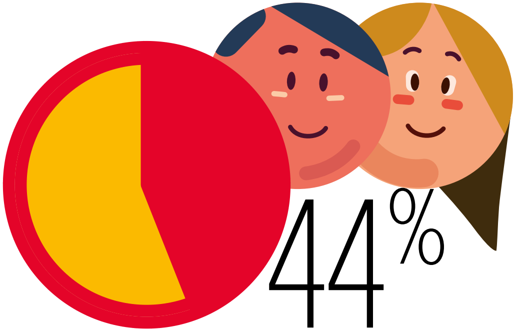
56%

are women.



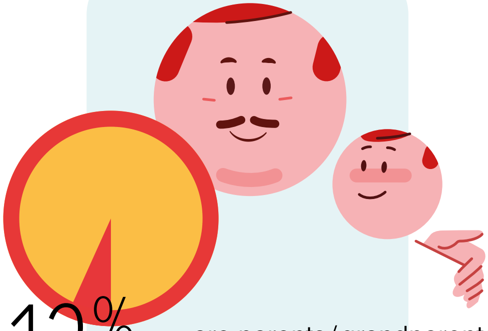
51%

are in paid employment.



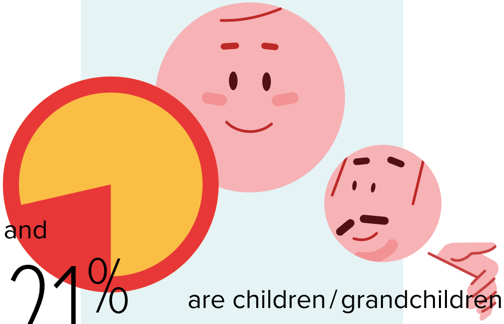
44%

are partners,



13%

are parents / grandparents (generally parents)

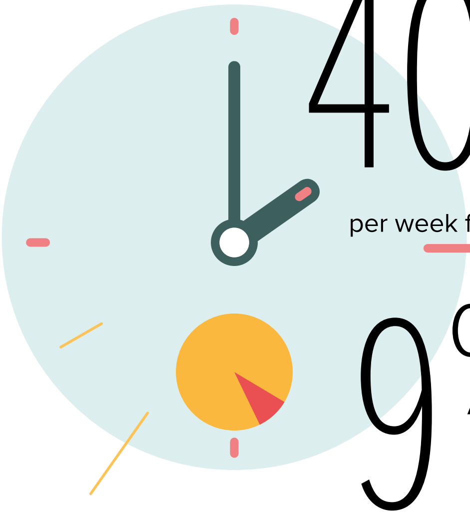


and

21%

are children / grandchildren (usually children).

The time devoted to caring can be just a few hours, but exceeds



40h

per week for

9%

of carers.

Dedicating part of your life to someone close to you who is more vulnerable then yourself is physically, mentally and emotionally demanding, and has an impact on your personal life.

THERE IS A RISK OF FORGETTING YOUR OWN NEEDS AND BURNING OUT.

We have put together this booklet to offer reassurance to carers, including tips to make aspects of your role easier and to help you look after yourself.

Amyloidosis

To carry out your role to the best of your abilities, you need to know the characteristics and main symptoms of the illness or impairment of the person you are caring for.

The AFCA publishes a regularly updated booklet for patients and carers called “Mieux connaître les amyloses” *[“For A Better Understanding Amyloidosis”]*.
It is written by experts from the reference centres and describes in simple (non-medical) language the different forms of the disease, its causes, how it is diagnosed, its symptoms and how it is treated.
The booklet is available to download from the AFCA website.
We can send you hard copies upon request.

The booklet is available to download from the AFCA website: ***www.amylose.asso.fr***

You can also give the booklet to GPs or nurses to help them better understand the disease and its impact.

The signs and symptoms of amyloidosis vary a great deal. However, all forms of the disease have a significant impact on the quality of life of the person affected and their carers. Most of the effects of amyloidosis are not directly visible.

Here, we focus on the difficulties these effects can create in the person's everyday life and the misunderstandings that can result.

Fatigue is found in all patients and is extreme.
The person's usual activities, including simple everyday tasks, become increasingly difficult. Family members can no longer expect the patient to be able to participate in family life to the same extent, and will need to work

together to fill in the gaps.
This can be particularly difficult for young children to understand.

Other symptoms vary from person to person, depending on the extent to which they are affected by the disease.
The most common include :

Dizziness caused by orthostatic hypotension (sudden drop in blood pressure when changing position) :
this affects many patients, meaning they have to stand up carefully.

Diarrhoea : this can be severe, unpredictable and exhausting, affecting the person's social life.

Oedema, particularly of the lower limbs:
this is often associated with kidney or heart failure, which are found in many patients

Other patients experience **weight loss**

Shortness of breath,
caused by the disease's impact on the heart : this can occur with less and less exertion and even when the person is at rest.

For patients whose nervous system is affected :

- **Pins and needles ;**

- **Loss of sensitivity to hot and cold :** this can cause clumsiness and accidents, leading to minor injuries ;

- **Pain** (burning or electric shock sensation).

These nervous system symptoms can cause clumsiness and minor injuries.
They are also accompanied by weakness, which can lead to falls.

Tiredness when walking
and **loss of balance**:
these can require the use of an aid (e.g. a stick), which can sometimes be difficult for the patient to accept, even if it is needed to keep them safe.

Loss of taste is very common and can lead to loss of appetite. This symptom can come and go: something that was tasteless one day might taste delicious the next. The person may be viewed as “fussy” as a result.

Patients may also have to deal with treatment side effects on top of these problems.

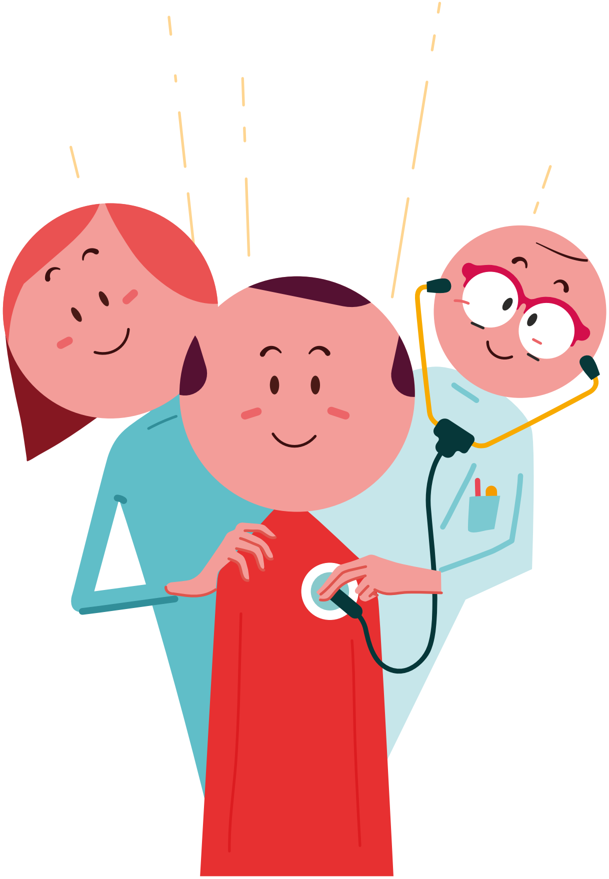
Questions, worries about the future, feelings of injustice (“why me?”), loss of independence, feeling like a burden on others and, for hereditary forms, the guilt of passing on the gene, are all difficult to bear.

Everyone reacts differently. For some, these tensions are expressed as fits of anger or aggression ; for others, as silence, resignation and gloominess.

The range of situations you may have to face is therefore varied, depending on the stage and nature of the disease and the patient’s state of mind.

CLEAR, PRECISE INFORMATION CAN MAKE THE SITUATION EASIER TO UNDERSTAND AND PROVIDE REASSURANCE THAT THE SYMPTOMS ARE NORMAL.

Nevertheless, the physical and emotional demands put you under significant pressure. To withstand this and be able to carry out your role, you need to lean to manage the situation over the long term.



What is a carer?

CARING NATURALLY:

IS IT NATURAL TO BE A CARER?

> *“Looking after our friends*
> *and family to keep them*
> *with us for as long as possible*
> *is a source of pride.*
> *I’d go so far as to say*
> *it’s an act of love.”*
>
> **JACQUES**

The term “carer” refers to any person, professional or otherwise, who cares for a dependent person, i.e. someone who requires help to complete essential everyday tasks or who needs checking on regularly.

A carer helps a frail person in a state of temporary or permanent dependence to remain in their own home, if they wish to do so, maintaining their standard of living.

The help provided changes over time: what was once occasional support may become essential care.

Professional carers

Professional carers, also known as personal care assistants, home helps, support assistants and live in carers, work in the home to support people who are losing their independence.
They are often qualified, and are trained to listen and offer advice. They play a role in the supported person's social life.

Non-professional carers

Non-professional carers are most often family members, in which case they are known as "family carers". Carers can also be friends or neighbours who have a close relationship with the person being cared for, in which case they are known as "friend carers".

The term "carer" does not have any legal status; it simply recognises a fact.
The term "natural carer" is also sometimes used in France, which unfortunately suggests that it is normal and natural to care for a close friend or family member.

The decision to become a family carer is often linked to living near or being emotionally close to the person requiring care.
Being a carer is tough: both your professional and personal lives are affected.
It can also create a psychological burden: one third of carers worry constantly about the person they care for.

Role of carers

**YOU DON'T CHOOSE
TO BE A CARER,
YOU JUST BECOME ONE.**

Carers provide company for the person they care for, as well as emotional and psychological support. This enables the person to continue to communicate and have a social life.

To begin with, you may offer help here and there, with things like the shopping or housework. But as the person loses their independence, you end up taking on a greater number of tasks and playing a much bigger role in their day-to-day life.

When it all becomes too much, you have to bring in professional help. It’s then down to you to organise and schedule the home visits from these various professionals: home helps, nurses, physiotherapists, occupational therapists etc.

If the person you are caring for has appointed you to be their legal representative, you will also attend their medical appointments and help with treatment decisions: you play an important role in their relationship with medical professionals. If they are unable to make decisions or express their opinion due to their medical condition, you will do so on their behalf. You may ultimately be granted power of attorney. (**www.simplifiezvouslavie.org**).

1. Everyday care

These are some of everyday tasks that you may undertake as a carer:

- Help with toileting, washing and dressing,
- Help getting into an armchair or bed,
- Preparing and administering meals,
- Administering medicines,
- Providing transport to and from home,
- Shopping,
- Buying medicines and personal care aids,
- Housework,
- Managing finances,
- Standing up for the person's rights, ensuring continuity of care,

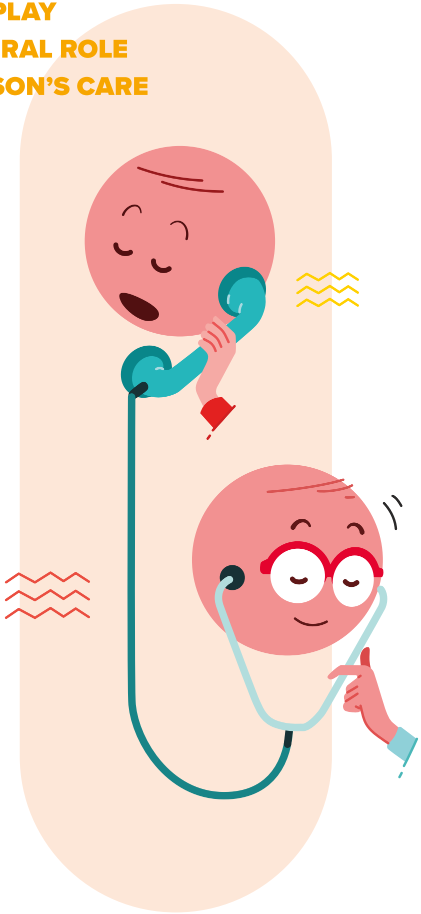
- Administrative and legal tasks,
- Attending appointments.

For tips and advice, see **Info Sheet 6 p. 149**

You may not be very familiar with some of these tasks, in which case it is important to:

- Ask professional carers to show you how to carry out various everyday tasks, so that you can complete them yourself if required at other times during the day
- Ask someone else who is close to the person you are caring for to take on some of the tasks (shopping, transport, administrative tasks etc.).

**CARERS PLAY
AN INTEGRAL ROLE
IN A PERSON'S CARE**



2. Interactions with medical professionals

Patient compliance with treatment depends on the level of trust between them and their doctor.
This relationship is often three-way: carer / patient / medical professionals.
Friends and family who look after the patient have an important role to play during medical appointments and can have a positive influence.

It is essential to have constructive interactions with medical professionals. A good relationship will benefit both parties.

For medical professionals:
based on the information you provide, they will gain a better understanding of the patient.

For patients and carers:
you will gain a better understanding of the medical issues.

Surveys conducted with patients immediately or a few days after appointments show that patients generally remember between 10% and 20% of what their doctor told them.

Attending appointments with the person you care for is therefore worthwhile:
you both hear the same things and you can add any details or fill in any gaps that they missed.

It is important to respect the patient's decision in the unlikely event that they do not want you to attend an appointment with them.

However, make sure you explain the value of having someone accompany them and the risks involved in potentially missing some of what the doctor says.

You could suggest that you just join them for the doctor's conclusions at the end, giving them time to have a more confidential discussion first.
See Info Sheet 2 p. 139

3. Treatment decisions

Consent is required from the patient for any decisions relating to treatments or examinations recommended by a doctor, provided the patient is conscious and able to express their wishes.
At the patient's request, you or the patient's legal representative can be included in discussions with their medical team.

If the patient is not able to express their

wishes, their legal representative must be consulted.
If they do not have a legal representative, this may fall to you, a member of the person's family or a close friend.
Your role is solely to express an opinion on the patient's behalf. The final decision will be made by the doctor.

4. Administrative tasks

You will very quickly be faced with a series of administrative tasks that you will need to get help with from the outset.

Your first port of call will be the GP, who will assess the person's loss of independence. The GP will then usually direct you to your nearest **CLIC** (Centre Local d'Information et de Coordination *[local coordination and*

information centre]). There are 600 of these across France. It might also be called a **CCAS** (Centre Communal d'Action Sociale *[municipal social support centre]*).
The centres are there to listen and offer advice, and can help you find practical solutions to everyday problems.

You can also get help from social workers attached to the local council or hospital. Another option is to contact charities, such as **the Association Française des Aidants** *[French Carers' Association]*.

Administrative tasks you may be faced with include :

- Making applications for financial support, such as APA (Allocation Personnalisée d'Autonomie *[personalised independence allowance]*) and AAH (Allocation Adulte Handicapé *[disabled adult's allowance]*)

- Applications for support from the **MDPH** (Maison Départementale des Personnes Handicapées *[departmental office for disabled persons]*): PCH (Prestation de Compensation du Handicap [disability compensation allowance]), disability card, priority access card, parking badge etc.

- Managing the person's paperwork : financial, bills, housing, tax, insurance, health insurance etc.

- Protecting the person's interests: applying for guardianship, power of attorney etc.

- Hiring and managing people to help in the home : nurses, support assistants, physiotherapists, occupational therapists, home helps etc.
- Adapting the person’s home.
- Organising temporary stays in a care home.
- When the moment comes, looking for a permanent care home.

For more information, please see
www.simplifiezvouslavie.org

The Association Française des Aidants

[French Carers’ Association] provides free online training to help carers with their daily tasks.
https://formation.aidants.fr

Boundaries of the role

BEING A CARER ISN'T
SOMETHING YOU LEARN,
IT'S SOMETHING
YOU EXPERIENCE.
BEING CARED FOR ISN'T
SOMETHING YOU CHOOSE,
IT'S SOMETHING
YOU LIVE WITH.

“My husband and I are both ill
and provide mutual support
to each other.
With a professional carer,
we have found the right balance.
Feeling useful to the other
person is a form of therapy.”

MARYSE

It is important to differentiate between cases where the carer and person being cared for are partners and those where they are child and parent.

In particular because, in the latter case, the child may now have their own family, who will also be affected.
The child’s family therefore need to be involved and taken into account.

Even in the case of a couple, there must be consent. “I should only do it if I feel able to and if I really want to.”

Sometimes, the whole family may get involved — children and grandchildren; sometimes, no one feels capable.
One possible solution is to use family mediation.
See Info Sheet 7 p. 151.

Whatever the circumstances, a friendly, balanced relationship needs to be established between carers, professional caring staff and the person being cared for, so that they can be given the best possible support.

1. **Mental health and relational issues**

To begin with, you will probably think that the person you are caring for has things hardest.

But little by little, you will discover that your own situation, while different, is also very difficult (and perhaps you had no more choice in this than them).

As time passes, you are at risk of suffering from stress and poor mental health.

There are multiple sources of stress:

- The development of dependency between you and the patient as a result of providing care.
- Restrictions on your time (you may be called upon 24/7)
- Unrealistic expectations (on both sides)
- Isolation (friends and even your own family may distance themselves)
- Difficulty keeping emotions in check, on both sides, which can have a negative impact on the relationship
- Forgetting to look after yourself.

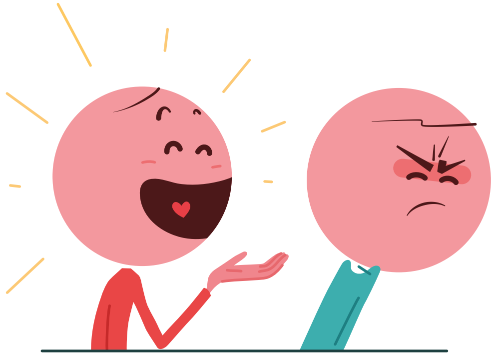
Bottling up your emotions in order to protect yourself or the person you are caring for can cause or worsen mental health problems and make it difficult to communicate with them.

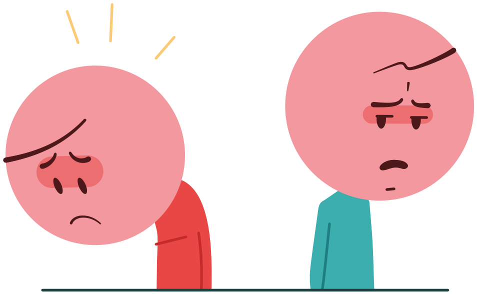
To be able to offer care in a mindful way, you need to stay clear-headed, including in relation to yourself, and make sure you attend to your health, your feelings and your emotions. Your well-being will have a positive impact on the other person, and you need to take your physical, mental and social well-being into account.

Moving from the status of “ill person” to “dependent person” shifts the context of the relationship. Some people may become authoritarian, even tyrannical. This can go as far as refusing to communicate or eat.

Changes like this are a reflection of physical or mental suffering, but also make it harder to be a carer and cause you pain.
So what should you do?
See info sheet 8 p. 154 for some tips.

“HIS PERSONALITY CHANGED. IT’S HARD TO KNOW HOW TO HANDLE IT.”





It is important to act, because if you continue to face these difficulties alone, you risk burn out, as does the entire family and the care team.

2. Listening to each other

Listening is the cornerstone of human relations.

“Everything is language” (Françoise Dolto): words, moans and gestures. Simply smiling or offering a hand is often more valuable than speaking.

Communication takes place even in silence.

It is important not to lose your sense of humour and togetherness, to continue to share memories and time together.

“Heal sometimes,
comfort often,
listen always.”

PASTEUR

When speaking is no longer possible, you can still communicate through looks, touching and even just by being present.

In the relationship between a carer and the person being cared for, an excessive desire to protect the other can make communication difficult.

The person being cared for may keep their worries, fears and pain to themselves to protect the carer, covering up how bad their condition has become.

They may feel guilty, which they may or may not express : “I’m ruining your life”. They may feel irritated by their dependence and take this out on the carer.

As the carer, you may feel like you’re dealing with a huge responsibility on your own. You may feel exhausted, but hide it so the person you're caring for doesn't feel bad.

It can be hard to talk about what's happening, your thoughts, needs and desires. You may feel unable to understand what's going on and severely affected by it.
Sometimes, it is only through speaking to a third party that the message can be decoded.

Finding time to talk to people who aren't involved in the situation can be a lifesaver for both parties, as it's a chance to express everything that isn't being said.

3. **Facing reality**

As the situation becomes worse, dialogue between the carer, the person being cared for and their medical team becomes essential. Discussions must be frank and direct.
There are various bioethics laws that can help shape and support these discussions.
Certain decisions will have to be taken, such as appointing the patient's legal representative and making an advance decision (living will).

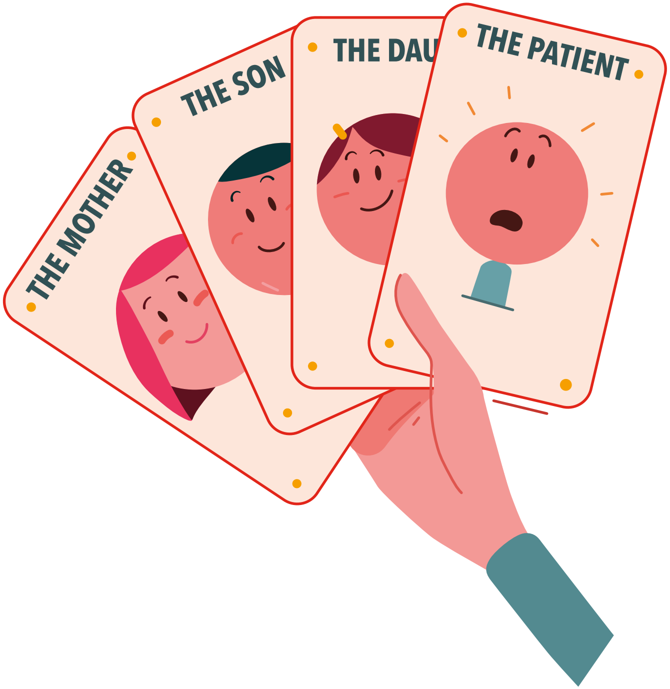
The mental load can become unbearable, leading you to neglect your own health.
Failure to acknowledge this burden can cause accidents, illness or depression.

4. Recognising when you've reached your limit

Carers may view putting the person they care for in a home as tantamount to abandoning them, and refuse to consider this as an option. However, to avoid getting to the point where you have no choice but to place the person in a home against their will, it is essential that you are able to identify when the time has come to consider residential care.
Here, too, guilt can read its head...

You need to remain focused on the facts: the person's level of independence, the type of care required, your ability to manage this — including with professional help — and the person's well-being (would they be better off in a home?).

Talking to doctors and the professionals providing support in the home (nurses, personal care assistants etc.) can help you get some perspective and see the situation more clearly.



5. **Family relations**

(different depending on who is the carer)

Illness affects different aspects of a person’s life, as well as the lives of their loved ones.

In the case of chronic conditions, which cause varying degrees of impairment and can require extensive medical attention, the family may need to be completely restructured.

The illness results in new ways of living and new ways of relating to partners and loved ones. In terms of the parent-child relationship, when the child becomes the carer, this inversion of the usual roles can be difficult to accept. This applies to both the carer and the person being cared for.

The situation can cause mixed emotions: sadness, anger, embarrassment, discomfort at the parent's diminished status.

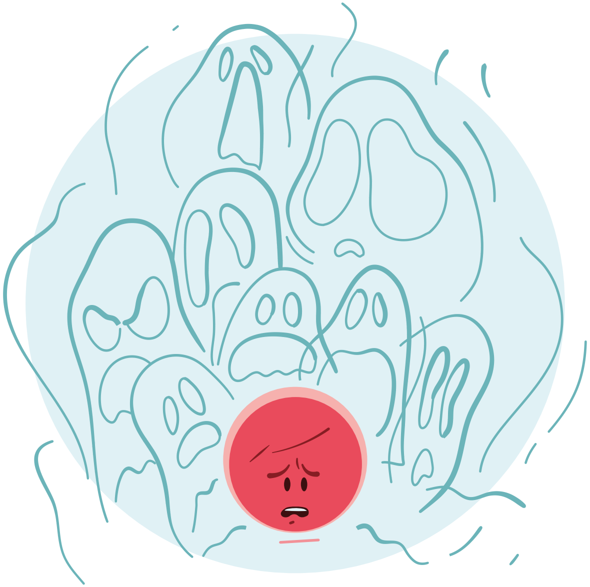
Illness inevitably impacts on relations between a couple. The status, roles and functions of each person are redistributed.

The relationship can quickly be reduced to carer / cared for. Each person's individual identity can be lost...
Nevertheless, illness does not preclude love, tenderness, a sense of togetherness and mutuality. Intimacy simply needs to be redefined.

Relations between the carer and the rest of the family can become fraught — particularly if the carer and the person being cared for are a couple — because families (including in-laws) are varied and complex.

However, the family's opinion can often provide a different perspective, removed from your day-today experience with your partner. They have the necessary distance to notice when something is changing or getting worse.

Make sure you also listen if they have concerns about your own wellbeing!



6. Feeling guilty, on both sides

The relationship between carer and person being cared for is not equal.

You may feel guilty for being healthy, for not being able do enough to help the other person, or for needing a break.

It is often hard for the other person to cope with becoming dependent.

It can be a good idea to seek outside help from someone who can offer an impartial and friendly ear.

This can take different forms for different people:
seeing a therapist, getting in touch with other patients or carers in similar situations

(charities can connect you free of charge), taking part in patient and carer education workshops (a good opportunity to meet people), or just confiding in a friend.

To maintain a good relationship with the person you are caring for over what often ends up being a long period of time, it is important to ask questions and voice any concerns.

7. Specific issues with hereditary amyloidosis

The hereditary nature of the disease is a particularly difficult burden for the patient to bear.
They may be aware of the experiences of older relatives and therefore know what to expect, which can be very worrying.

On top of this, the risk of transmitting the disease to their children is an additional source of anxiety and guilt.

The familial nature of the condition is also stressful for carers. You may be related to the patient yourself and run the risk of carrying the gene or, if you are their partner, you may share their concern for your children and current or future grandchildren.

If you are planning to have a child, the gene carrier can explore various solutions with your antenatal team.

In this situation, it is even more important to seek outside help from a therapist, for both you and the patient. Genetic counselling is provided by law in these circumstances. **See Info Sheet 9 p. 156.**

The importance of looking after yourself

WHAT'S THE BEST WAY TO CARE FOR A SICK LOVED ONE WITHOUT NEGLECTING YOURSELF?

Caring for an ill or disabled loved one can be an enriching adventure on a human level, but it can also have a detrimental impact on you, as you are often forced to put your life on hold.
It is not possible to stay smiling, attentive and caring if you are exhausted or overwhelmed by day-to-day tasks. It is essential to look after yourself if you want to remain truly able to support your loved one.

You face a huge number of challenges.

Make sure you get some respite from caring: take some time for yourself, exercise, maintain your social life and, most importantly, look after your own health.

According to the **WHO** (World Health Organisation): “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.

These moments of respite are essential: if you are exhausted, you will not be able to maintain your usual caring attitude towards your loved one.

To keep supporting them to the best of your ability, you need to take some time for yourself.

There are plenty of solutions to choose from, including for carers who are also in paid employment. For details, see:
www.simplifiezvouslavie.org

Take it from us!

Caring for a loved one is a powerful, intense, sometimes stressful life experience. Your relationship with your loved one is complex, developed over many years, with its own secrets and codes of behaviour.

Learn how to create moments of fun between you, surprise them and surprise yourself.

Helpful websites:

https://essentiel-autonomie.humanis.com/aider-un-proche/web-serie/culpabilite-s-installe-dans-vie-aidant

https://aidantattitude.fr/

1. Setting boundaries for yourself

Taking care of a loved one day after day is a major investment for most carers, with an impact on their quality of life. Faced with mounting responsibilities and a lack of time for yourself and your family, you can feel alone and unable to deal with the impact of lost independence and uncertainty about the future. As we saw above, you may even feel guilty on top of all the tiredness.

It is essential to set boundaries for yourself. Many carers are scared of seeming like they lack empathy or aren't giving enough, and so suffer in silence, not wishing to inconvenience their family.

It is always best to confide in someone, share how you're feeling, ask for help from family

and, where possible, bring in professional carers.

Don’t allow yourself to become overwhelmed by feelings of helplessness when faced with the difficulties involved in caring for your loved one.

Accept your feelings. Having negative emotions does not mean that you are incapable of providing good care.

“I daren’t go out except
to do the shopping.
I feel like a prisoner.”

LUC

"I have arranged for my neighbour to stop by when I'm not there, so I can keep going to my painting classes on Tuesday mornings. I get back full of energy for the rest of the week."

JOSETTE

You need to take regular breaks each day. Set aside some time for you. Don't wait until you're exhausted to think about this. Consider your own needs and do things that are focused on you. As well as giving you the strength to carry on, the time you take for yourself will help you feel less alone.

Don't forget to spend precious time with your children or family.

Make the most of life and try to take breaks that are enjoyable and fun. They may not happen as often, but they are still possible and they benefit everyone!

2. Using professional carers for personal care tasks

When looking after your loved one becomes too challenging, your next step is to find professionals to help with all medical care and personal care tasks (toileting, washing and dressing).

For the dependent person who can no longer go to the toilet or wash themselves, reaching this stage in their loss of independence can be very tough. Helping someone go to the toilet or wash themselves is not simply about hygiene. It means the carer becoming intimately involved with the other person.

Personal care assistants help dependent people complete these tasks in their own home.

Hiring a personal care assistant can prevent mutual embarrassment and help maintain love and affection.

There are three types of professional qualified to assist dependent people in their homes in France : home helps, support assistants and care assistants (“AVS”).
Care assistants are the most highly qualified and take on a wider variety of tasks.
They help the person they care for with all their day-today tasks (toileting and washing, meals, taking medicines, moving around), aside from medical care, which must be delivered by nurses or nursing auxiliaries.
They make sure the person is comfortable and attend to their well-being.

“It’s not easy for me, his daughter, to have to see my father naked. He also finds it difficult. Fortunately, his assistant takes charge of his main day-to-day care needs.”

MARIE

Carers and professional care workers who help in the home find themselves in a delicate situation where each is exposed to the critical eye of the other: the professional may judge how the carer does things and how they relate to the person being cared for, while the carer may judge how patient the professional is with their client. Care workers have technical expertise, while you as the carer have personal knowledge of your loved one.
Both are essential to the well-being of the person being cared for.

It is important to establish a trusting relationship with care workers. They have the skills required to help you support your loved with every day-to-day task. The most important thing is that the person being cared for is happy with the emotional and practical care they receive.

Nursing care in the home is covered by health insurance when prescribed by a medical professional.

To receive financial support to pay for a care worker, the person requiring care can apply for **PCH** (Prestation de Compensation du Handicap *[disability compensation allowance]*) if they are under 60 years of age, or **APA** (Allocation Personnalisée d'Autonomie [personalised independence allowance]) if they are over 60.
There is no means testing for these benefits, but the amount awarded depends on income.
The person you are caring for may also be able to apply to their pension or health insurance provider, which may offer a personalised support plan, subject to assessment.

For more information, please see **www.simplifiezvouslavie.org**

If your loved one does not want a care worker, tell them that it is you who needs help, so you can better look after them.

> *"To begin with, I wanted to do everything, but then I was admitted to hospital and my children had to take over for a few days in my absence. On my return, they suggested taking turns to come for a half day. I use the time to go for a long walk or to the cinema. My husband is happy to be looked after and I've got a new lease of life now I have a bit of time to myself."*

JEANINE

3. Continuing leisure activities and maintaining your social life

Not all carers are retired!
It is possible to continue to work while you care for someone — provided that they retain a certain level of independence — as French labour law makes certain allowances for carers (make sure you speak to your employer).
Professionals such as nurses, care workers and physiotherapists can fill in while you are at work.
More on **www.simplifiezvouslavie.org**.

Whether or not you work, you can quickly find yourself overwhelmed by the extent of your caring duties, and may neglect your health, family, friends and job. Continuing your usual leisure activities and maintaining your social life will help keep you balanced and well, reducing the impact of tiredness and increasing your ability to face difficult challenges.

However, making time for yourself can be complicated. The desire has to be there, and you will need to consider whether you can accept that you are not the only person capable of looking after your loved one. Depending on how disabled the person you are caring for is, look into getting some temporary respite, using a live-in carer or day centre. You will benefit from a few hours off and your loved one from a change of routine. Make sure that they have all the professional support they need and will be able to manage without you.

3. a. **Continue your leisure activities**

While your loved one is being cared for by professionals, dedicate some time to activities that help you feel good: reading, going to the cinema, shopping, walking, physical activity, seeing friends or spending time with your children.

As far as possible, make sure you also do things with the person you are caring for: read them the newspaper or a book you both like, watch a good film together on the TV, look through photo albums and ask them to share their memories, play a board game, go for a walk (if they still can), and so on.

3. b. **Get active**

Whenever you move your body in a way that expends energy, this counts as physical activity. Sports are one option, but physical activities like DIY, gardening and walking also improve your general wellbeing.

Taking care of your own body will help you manage better day to day and have a better relationship with your loved one.
Choose an activity that you enjoy and can do at your own pace: jogging, Nordic walking, cycling, walking, going to the gym, relaxation etc. Physical activity is not only a chance to get a break: it can help you relax and boost your well-being.

3. c. **Maintain your social life**

Make sure you don’t let your own social life slide. Get organised and reconnect with your friends and family.
Accept invitations and go out.

It is also important to ensure the person you are caring for has a social life, for both your and their well-being.
Invite their friends and family to come and visit, if they are happy with this.

4. Keeping life as normal as possible and making the most of what they can do

In an effort to help the person you are caring for or save time, you may be tempted to do things for them.

Remember that maintaining as much independence as possible and/or taking part in normal family life is important to them. Even if a simple task is hard for them and takes them much longer than it would take you, allow them to do what they want and are able to do on their own.

Combining your social life with your role as a carer will have a positive impact on your relationship with your loved one.

“You need to accept that
your mum is not the same
as before she got ill,
but she’s still your mum.
Share all the little things
that make her happy with her:
you’ll feel better and that’s how
you get your revenge on
the disease.”

JEAN-PIERRE

5. Getting your friends and family involved

Don’t fall into the isolation trap: taking everything on yourself, not asking for help, not talking to anyone and blaming yourself for not doing enough.

Making connections and getting friends, family and neighbours involved will help you avoid this pitfall. Other people close to the person you are looking after will want to help out or show that they care. Taking care not to exclude them will benefit both them and the person being cared for.

AS A CARER, YOU ARE UNIQUE, BUT YOU ARE NOT ALONE.

“Every Thursday,
I drive Paul to the physio:
his wife doesn’t have a licence.
I use the time to do my shopping
at the supermarket.”

JACQUES, Paul’s neighbour.

“I’m a remote carer.
My parents live 500 km away.
I track my mum’s condition daily
over the phone as it progresses
and I try to assess my dad’s
capacity to continue to care for
her, so I can anticipate
any problems.
I try to step back, even though
it feels like I’m becoming a parent
to my parents.”

ÉLISABETH

Without making it seem like you are complaining, you can clearly express which needs you are unable to meet or where you are feeling overburdened.

It is very common for carers to feel alone and it helps to work as a team alongside professional care workers.

An effective team is one that communicates regularly and in which everyone has a clear idea of their roles and limits.

See info sheet 5 p. 147 for tips on organising care efficiently.

6. Be aware of your own health

You don’t need to be constantly monitoring yourself, but you do need to watch out for minor issues that may turn out to be an additional source of stress if they go ignored.

7. Right to respite

That are various different ways to get cover for the care you provide so that you can take a few hours or days off to recharge your batteries, enabling you to keep going.

A friend or family member may want to take over. Let them.
Out of love or affection for the patient or for you, they may have a personal need to help and you shouldn’t deny them this.

There are local organisations that can provide volunteers : ask your local council, healthcare workers, social workers, patient associations etc.

Care homes can also offer respite :
old people’s homes offer temporary places and there are holiday homes for people needing care and their carers where you can have a few hours to yourself each day. Contact your health insurance company or relevant charities for more information.

**YOUR ROLE
IS ESSENTIAL.
YOUR WORK IS VITAL.
TAKE CARE
OF YOURSELF.**

Common questions

HOW TO OPTIMIZE SUPPORT FOR A SICK LOVED ONE?

1. Is my loved one receiving the best possible care?

Care for people with rare diseases is more complex, because the conditions are not well understood.

There are several different aspects of patient care that need to be considered :

- Diagnosis, monitoring and treatment.
- Personal care and the coordination of this care.
- Emotional support.
- Social, professional and financial support.

Both you and the patient will want to ensure all these aspects are addressed in the best possible way.

1.a. Medical care

The patient can choose their own doctor. It is important that the patient feels able to trust their doctor. As their carer, you may need to provide reassurance that they are receiving the best quality medical care.

Don’t be afraid to ask for a second opinion.

You may find the following information helpful.

Since 2005, there have been three successive nationwide programmes in France to deal with rare diseases.

As part of these programmes, reference centres have been set up to establish national diagnostic and care protocols and to oversee a regional network of specialist centres.

There are four reference centres for amyloidosis, covering different forms of the disease.

The booklet “Mieux connaitre les amyloses” *[“Understanding Amyloidosis”]* can be downloaded from the AFCA website and contains the contact details for all these centres.

Do get in touch with the AFCA if you need further information.

1.b. **Personal care**

Patients with amyloidosis often require more than just medical care. Support staff have a key role to play.
Family carers are often viewed as part of this team and, as such, you will be working in partnership with professional staff.

You are the natural link between all those helping to provide care, given that you have regular contact with the patient and a detailed understanding of their medical needs and general situation.

Providing coordination through regular communication with everyone involved improves the quality of care, since it gives each person a better picture of the situation, enabling them to carry out their own role more effectively.

1.c. **Emotional support**

As detailed earlier in this booklet, both patient and carer can end up feeling emotionally isolated.

For both of you, expressing your anxiety, anger and frustration is crucial for self-care and necessary if you are to keep the relationship on a healthy footing and your interactions pleasant.

Don’t be afraid to seek outside help.

The hospital department responsible for the patient may be able to offer support from a psychologist: speak to the care coordinator to find out.

The AFCA keeps a directory of local support services. It also provides free telephone counselling for AFCA members.

In addition, it can provide you with a list of other patients or carers, so that you can have informal telephone conversations with people going through similar situations.

1.d. Social, professional and financial support

You can find key information on these areas of care in the resources available on the AFCA website and those mentioned in this booklet.

www.simplifiezvouslavie.org

2. Worries and concerns

The sense that the future of the person you are caring for is completely dependent on you is an additional source of stress.

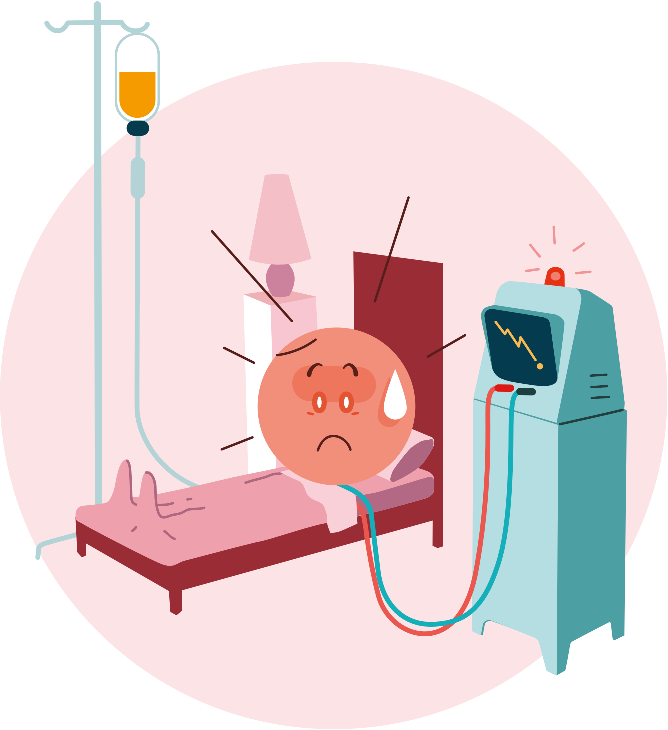
You may have many different questions going round in your head:

Will I be resilient enough to keep caring for them right to the end?

What will happen to them if I get ill?

And so on…

Support from your family and friends again comes in crucial. They can look after you so that you can keep looking after the other person.



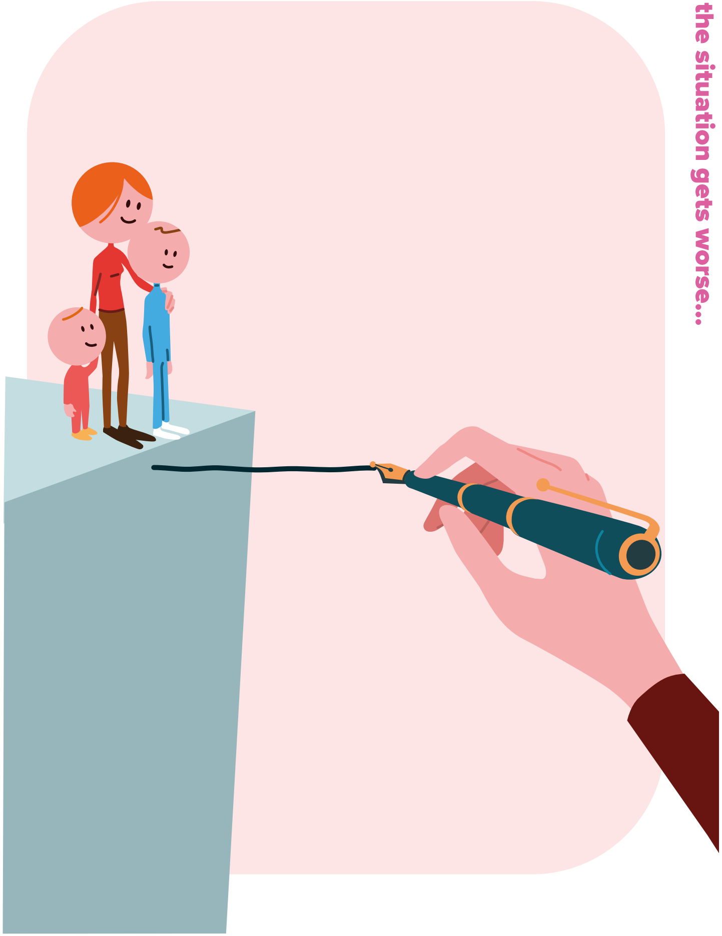
If
the situation gets worse...

**TO PRESERVE THEMSELVES,
THE CAREGIVER MUST PREPARE.**

1. Difficult conversations with your loved one

It is unusual to spend time worrying about serious life events that might happen in the future, and even the most forward-thinking people are rarely prepared for these kinds of situations.

When someone gets ill, if the person themselves is not making plans for when their condition may deteriorate, it can be difficult for friends and family to know how to bring this up with them.
They may worry about causing the patient anxiety if they discuss loss of independence or end of life.



However, not knowing the patient's wishes, and / or not having the documentation to ensure these are respected can be worrying for both you and the patient's other family and friends.

It is reasonable to want some clarification on these issues and to be concerned about them.

You could ask for outside help from someone (psychologist, professional carer etc.) who is better placed to make the person understand that you and the family are taking a responsible approach in wanting the patient to express their wishes.

2. **Palliative care**

When the illness progresses to the point where there is only one outcome, it's time to consider more appropriate care.

Don't rule out this option :
professional palliative care provides physical relief that allows the patient, you and the whole family to get through this difficult time as peacefully as possible.

In addition to specialist hospital departments, there are teams that can provide this care in the home if the patient prefers.

The patient's doctor is the person to contact if you wish to start palliative care.

3. Respecting the patient's wishes

If the patient is unable to express their wishes, is at the end of life and has not written an advance decision **(see info sheet 3 p. 142)**, the patient's legal representative becomes their spokesperson and can give consent to doctors on their behalf, in particular with regard to prolonging, withholding or withdrawing treatment.

After consulting with the patient's legal representative, doctors cannot withhold or withdraw treatment until they have formally consulted with other doctors and the patient's care team, through what is known as a "collegial procedure".
See info sheet 4 p. 145.

"She took care of me.
Now it's my turn to take care
of her: I do her shopping,
cook her meals, take her out
to places.
And once she has gone,
it will leave an enormous hole."

NATHALIE

4. **Afterwards**

In the most difficult cases, caring for the other person becomes a full time job, and it can be difficult to see the bigger picture.

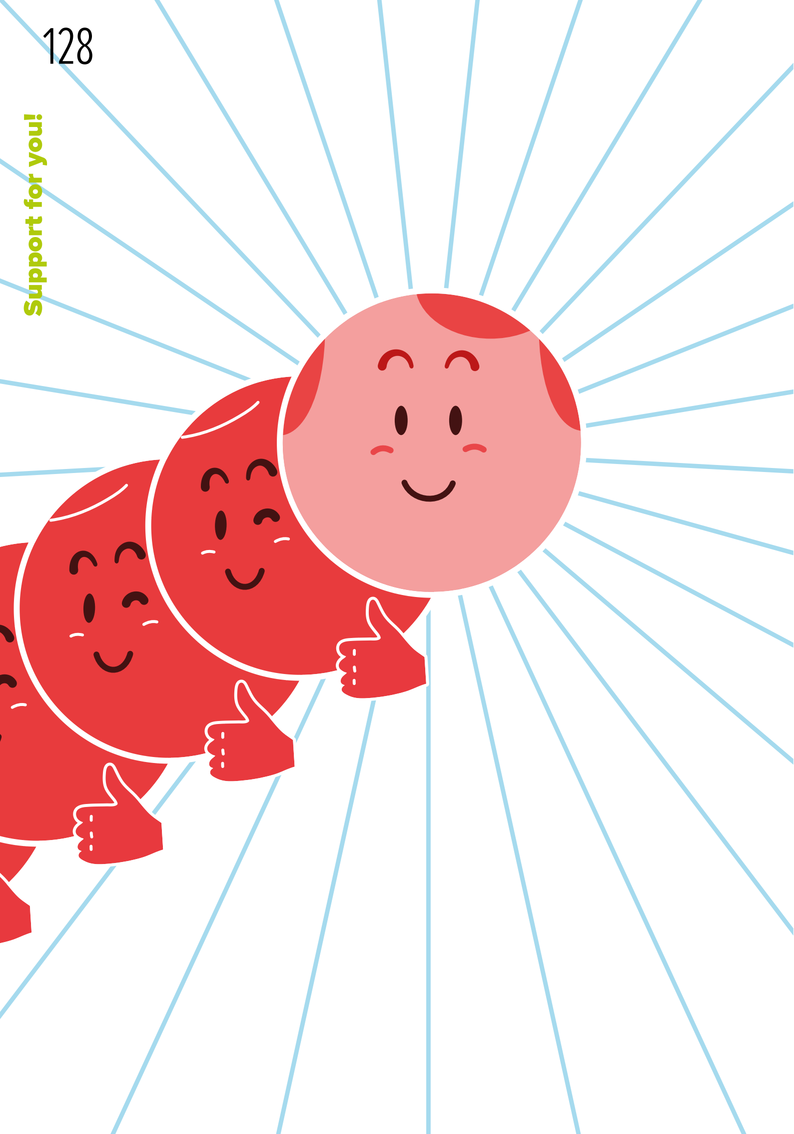
But for your own sake, you need to mentally prepare for any eventuality.

Losing your loved one is different depending on whether you are their partner or a relative. Grief is inevitable. You need to take some time to rest and rethink your life. Family support remains essential.

For partners used to a very demanding caring role, your days are suddenly empty and it is important not to let your children immediately turn you into the one needing care!

The family unit must not be destabilised or undermined by well-meaning acts of support.

For children losing a parent, the impact of the emotional shock is different. The sense of loss is less keenly felt on a day-to-day basis, instead developing over time. Everyday life (work, family, leisure) goes on.



Support for you!

IT'S NOT JUST ILL PEOPLE WHO NEED HELP. THE EMOTIONAL BURDEN YOU CARRY AS A CARER MAKES HUMAN CONTACT AND INTERACTION ESSENTIAL.

1. The AFCA

Telephone support:
some of the AFCA's members are willing to share their experiences. It can be comforting and reassuring to talk to people who are going through or have been through the same thing.
You can talk more openly to someone who is not a friend or family member of the person you are caring for : you can discuss difficulties and worries without feeling like you have to protect the other person.
We have several enthusiastic and positive volunteers available to talk to anyone who needs it. Volunteers either have a form of amyloidosis or are a carer like you.

Simply call the AFCA and we will put you in touch with a volunteer who is going through or has been through a similar situation.

The AFCA's psychologist has an in-depth understanding of amyloidosis and what life is like as a carer. She can provide personalised psychological support by telephone for just one or two sessions or over the longer term, depending on what you need.
Call us and we will put you in touch with her so you can arrange a telephone session.

2. Patient and carer education programmes

Taking part in patient and carer education workshops can be a huge help in managing your day-today caring duties, with advice on topics such as daily routine and diet.
The programmes cover all aspects of caring and give you an opportunity to discuss both common and specific situations, as well as

to benefit from professional advice and the experiences of other carers.

They are also a good way to feel less lonely. The workshops are a chance to talk to healthcare professionals and families going through similar situations.

Carers can attend with or without the person they care for, and certain workshops are specifically dedicated to carers.

At present, the programmes are only available in certain hospital departments. Further programmes and online access will be introduced in the future.

3. Carers’ network

There are many similarities in the role of carer, regardless of the illness involved. In response to the isolation faced by so many, carers have joined forces to support each other and share tips and tricks.
There are several websites dedicated to this, including: **www.lacompagniedesaidants.org**

Take it from us! A quiz to work out what kind of carer you are.

Getting to know yourself better will help you get better at self-care :

https://essentiel-autonomie.humanis.com/quel-fred-etes-vous?

Info sheets

INFO SHEET 1

ADMINISTRATIVE TASKS

The AFCA has worked with legal experts and other professionals to develop a tool that outlines all the rights of patients and carers and provides practical advice for administrative tasks.

You can access it at:

www.simplifiezvouslavie.org

INFO SHEET 2

MEDICAL RECORD AND APPOINTMENTS

Advice taken from the **REMEDE** study, which looked at the relationship between doctors and the patient’s family :

- To improve communication with the medical team and the person you are caring for, encourage collaboration, take an active role in their care, develop mutual understanding and make your presence known to care staff

- Keep an up-to-date medical record, with the patient’s consent, containing personal, medical, administrative and legal information

- Record the contact details of healthcare professionals and the dates of appointments with them
- Record the patient’s symptoms each day (overall well-being, pain, treatments etc.)
- Keep an up-to-date list of treatments and prescriptions
- Ahead of appointments, prepare a list of questions for the doctor with the person you are caring for
- Listen to the doctor carefully, let your loved one express themselves, don’t be afraid to ask for further explanation if something isn’t clear
- Talk to your loved one after the appointment to compare notes on the information you were given. If you don’t agree on something, work out why, decide how important it is, and don’t be afraid to ask the doctor to help you find a compromise
- Check that any medicines provided by a pharmacist match the prescription
- Make sure you talk to the doctor about any impacts on your own quality of life.

INFO SHEET 3

ADVANCE DECISIONS

Under the French Leonetti Act of 2005, any adult can express in writing their wishes regarding their end-of-life medical care. This may involve the refusal of care that would artificially prolong their life, and whether or not they wish to receive palliative care.

Since 2016, “advance decisions” expressing the patient’s wishes are one of the first things to be considered by doctors when deciding whether to continue or withdraw treatment as part of the “collegial procedure” consultation process.

It can be difficult to make decisions about end-of-life conditions in advance.

However, advance decisions are designed to ensure that the patient’s wishes are respected.

When drawing up an advance decision, it is important for the patient to talk to their family, legal representative and, in particular, their doctor, to make sure they understand the treatment options and consequences.
A template advance decision is available here:

https://www.service-public.fr/particuliers/vosdroits/R44952

The content of an advance decision takes precedence over all other opinions, including that of the patient’s carer or legal representative. Your role as a carer is therefore to ensure that your loved one’s wishes are respected.

If no advance decision has been drawn up, the doctor will listen to the opinions of the patient’s legal representative, family or close friends.

https://solidarites-sante.gouv.fr/soins-et-maladies/prises-en-charge-specialisees/findevie/pour-les-professionnels-de-sante/fiches-pratiques-a-destination-des-professionnels-de-la-sante/article/le-renforcement-de-la-collegialite-dans-les-decisions-en-fin-de-vie

www.simplifiezvouslavie.org

INFO SHEET 4

COLLEGIAL PROCEDURE

The French law of 2 February 2016 extended the range of circumstances in which a collegial procedure (formal consultation with a patient’s medical team) must be undertaken prior to making an end-of-life decision. Doctors must undertake a collegial procedure in three situations:

1. When the person at the end of their life is unable to express their wishes and the doctor is considering withholding or withdrawing treatment that is deemed ineffective, disproportionate or to have no impact other than artificially prolonging life.

2. When the doctor intends not to comply with an advance decision that he or she deems to be manifestly inappropriate

or irrelevant to the medical situation.

3. When analgesia and continuous deep sedation until death is being considered, either at the request of the end-of-life patient or by the doctor on behalf of a person who is unable to express themselves, alongside the withholding or withdrawal of treatment.

The collegial procedure consists of three phases:

1. Assessing the situation with the patient's medical team based on medical criteria
2. Establishing the patient's wishes based on their advance decision or, if no advance decision has been made, by talking to their family
3. The doctor will then make a reasoned decision and inform the patient's loved ones.

INFO SHEET 5

MAKING A CARE SCHEDULE

Start by listing all the people who are able to help (family, friends and neighbours, as well as outside help) and their availability, skills and wishes.

Alongside this, list all the patient's needs of any kind (equipment, mobility, financial resources etc.): talk to professionals and charities to help you draw up the list and identify how it might change over the medium term. Make sure you include everything you can think of, including things that may seem trivial.

Draw up a draft proposal for who will meet each need (do this together, if possible) and check that everyone is happy with what they have been allocated to do: unless everyone is on board, the plan will soon fall apart.

Display the schedule somewhere and share it with everyone involved. Add a list of everyone's contact details, to make it easier to communicate and to organise cover at short notice.

Stay in regular contact with everyone involved so that they feel supported and can let you know if they have anything to report or any ideas for improvement.
Involve them in any changes.

INFO SHEET 6

TIPS, TRICKS AND TOOLS TO MAKE EVERYDAY LIFE EASIER

If possible, set aside an area in the house or flat that does not get turned into a hospital and is not open to professional carers.

Leave out a notebook that can be used to communicate with professional carers.

Draw up:

- A list of all useful contacts (doctors, other medical and caring professionals, close friends and family etc.)
- A calendar of appointments/examinations (for the year)
- A schedule for a typical week/day

- Invite the neighbours over for drinks to let them know what's happening, so they can keep an eye out.
- Buy clothes that are easy to put on.

INFO SHEET 7

PROBLEMS WITHIN THE FAMILY : FAMILY MEDIATION

Family mediation is an amicable process that is being trialled until the end of 2019.

It can play a valuable role in managing relations between family members in a difficult situation, helping to keep channels of communication open.

It is a solution worth trying before the situation gets too complicated or tense.

The mediator will help you get some perspective and will be able to offer up ideas based on their knowledge and experience, while facilitating dialogue between everyone involved. They will support each person to reflect on their role and the impact of the responsibilities they have taken on.

How to access mediation?

One of the people involved will need to lodge a request with an organisation authorised to provide mediation.

Mediation cannot begin until everyone involved has agreed to participate.

Mediation will primarily involve discussions between all the parties.

The following organisations can help you access mediation:

- **FENAMEF** *[French National Federation of Family Mediation Associations]*
- Unions Départementales des Associations Familiales (**UDAF** *[departmental family association unions]*)
- Specialist charities (for carers, disabled people, families)
- Caisses d'Allocations Familiales (**CAF**, family benefit offices).

INFO SHEET 8

KEEPING THINGS FRIENDLY

People needing care have been impacted by both their physical problems and a succession of losses (work, independence, sometimes friends): their whole world has changed.

Aggression or silence can often mask physical or emotional suffering. So how can carers work out what's happening and what's the best way to respond?

Avoid asking too many direct questions, listen, observe and try to work out what has changed (new treatment or source of physical discomfort, changes to their daily routine, change of attitude in a loved one, new professional carer etc.).

If you think you have identified a problem, avoid the kind of clichés that make it seem like you are minimising the problem or don't understand ("it's nothing", "you just need to", "why don't you" etc.).

Talk to the other person and try to calmly assess the situation in order to put things in perspective.

Show your empathy through affection, but don't go over the top.

Seek help through carer education workshops or from a psychologist to help you manage the situation.

INFO SHEET 9

GENETIC TESTING

Both people with a disease and their relatives can benefit from genetic counselling. Genetic transmission of amyloidosis is “autosomal dominant”, meaning the children and siblings of a person with the disease have a 50% risk of carrying the genetic mutation.

At-risk relatives over the age of 18 can identify their genetic status before any symptoms appear, through a pre-symptomatic genetic test that determines whether the person carries the mutation and is therefore at risk of suffering from the disease.

The aim of genetic counselling is to enable the person to make an informed, independent choice as to whether to undergo genetic testing.

If the person knows their genetic status, the disease can be diagnosed as soon as the first clinical signs appear and appropriate treatment can be started early on.

Genetic testing is prescribed by a multidisciplinary team with a range of clinical and genetic expertise.
Each team has a treatment protocol and reports to the French Biomedicine Agency (Article R1131-5 of the French Public Health Code), which follows international guidelines.

Several appointments are involved.
This provides time and space to absorb the information and reflect on the genetic risk, the disease itself and the future, and helps stop the person reducing themselves to a genetic test result.

Genetic counselling is a responsible option for both you and your relatives.

It is dedicated to the family as a whole and takes place over several sessions.

It can also be used to look at advances in treatment and the possibility of assisted reproduction (prenatal diagnosis or pre-implantation diagnosis) for those who want it. This decision is made entirely by the couple.

A law was passed in France in 2013 requiring patients with genetic conditions to inform all those in their family who could potentially carry the gene.
Carers can support the patient with this delicate process — one that can result in family conflict.

The AFCA can provide a template letter for informing relatives and recording the contact details of those affected.

If the patient refuses to comply with this legal obligation, the doctor becomes responsible for doing so.
In this case, the carer can provide the doctor with a list of people to inform.

Table of contents

2. Patient and carer

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