MPe Myeloma Patients Europe

Question & Answer

MYELOMA PATIENTS EUROPE

Living with AL amyloidosis

www.mpeurope.org

Edition: Myeloma Patients Europe (MPE)

Updated: March 2023

Myeloma Patients Europe AISBL
Avenue Louise 143/4
1050 Brussels
Belgium

www.mpeurope.org
info@mpeurope.org

Table of content

AL amyloidosis (also referred to as light chain amyloidosis) is a rare disease that arises from abnormal plasma cells, which are a type of immune cell responsible for antibody production. These abnormal plasma cells produce abnormal proteins which are deposited in organs and tissues, leading to organ disfunction. This Q&A covers the most frequently asked questions related to living with AL amyloidosis.

Will I be able to work if I have AL amyloidosis? 4

What changes should I expect in my life?....4

Are there any changes I should expect in how I see myself or how people see me after receiving my diagnosis? 5

Will I need to rely on a caregiver due to my condition? 5

What kind of help and support might my caregiver need? 6

Can I exercise if I have AL amyloidosis?....6

Does nutrition play a part in AL amyloidosis and its treatment? 7

What can I do to preserve my physical health and wellbeing beyond available treatment options? 7

Will AL amyloidosis influence my sexual and reproductive health? 7

Will the treatment affect my sexual and reproductive health? 8

What can I do to preserve my mental health after I've received a diagnosis of AL amyloidosis? 9

What is palliative care and when should I consider it? 9

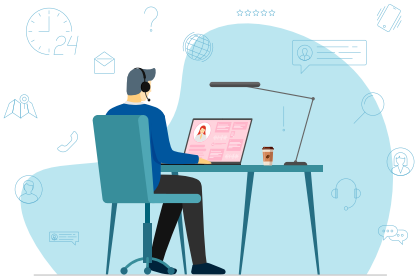
Where can I turn to for support and more information? 10

References 11

This is not intended to be medical advice. Please speak with your clinician, if you have any questions or concerns about your disease.

Will I be able to work if I have AL amyloidosis?

You may choose to continue working after receiving your diagnosis, however, you should keep in mind that it may be necessary to take time off work for tests and treatments, possibly involving extended hospital stays. It will also depend on the type of employment (more or less "physical") you are in. You can discuss your diagnosis with your employer, but this is not an obligation. Many employers may be open to adopting flexible approach to working conditions and reducing the level of responsibility should that be required. However, it is possible that your illness will affect your ability to stay in a working environment at all. In this case, governmental support may be available, and you might be eligible for certain benefits. These vary from country to country, but in many cases provide for a living or personal independence allowance, support to pay for a carer, or a tax allowance. Patients who continue working may be entitled to a statutory support allowance, if they are not eligible for sick pay from their employer. Relatives or friends looking after a patient may be able to claim a carer's allowance.



What changes should I expect in my life?

As AL amyloidosis may affect several organs in your body, there might be changes in your life that are necessary and unavoidable. If you are receiving treatment, these changes may be complemented by additional adjustments and constraints that arise from the treatment, or its side effects. Discomfort is common with AL amyloidosis, and so are inexplicable bouts of fatigue, cramps and fluid retention. If you are experiencing these symptoms, consider consulting your doctor, as one of the most important changes may be that you need to spend more time in medical consultations. For example, the dara-CyBorD treatment combination (daratumumab, cyclophosphamide, bortezomib and dexamethasone) is given once a week for six months. Blood tests and doctor consultations are performed once a month. The treatment is then given once a month, and blood tests and doctor consultations every two months. During follow-up, consultations can be less frequent (every 3-4 months), or even once every 6-12 months for patients still in remission late after an autologous stem cell transplant. You may need to reduce or reschedule your daily activity and find ways to accommodate fatigue or feeling weak, for example. Try to adapt a mild exercise regimen (see "Can I exercise if I have AL amyloidosis?") as that will improve your health, and help you cope with the illness and the treatment as well.

There may also be changes in your physical appearance. Common, visible changes include fluid retention, which can cause swelling and an enlarged abdomen, skin changes, such as easy bruising or purple discoloration in the skin folds and/

or around the eyes (also called periorbital purpura), as well as brittle nails. Such bodily changes sometimes also lead to reduced self-esteem and confidence, and so psychological support may be necessary to cope with these. In some cases, you may need support with your usual activities, like bathing or getting around. Discuss these with your family or friends and seek help from patient organisations, or your healthcare providers as much as possible.

Are there any changes I should expect in how I see myself or how people see me after receiving my diagnosis?

Receiving any diagnosis is always a life-changing event. Even if you are no longer young, you certainly have dreams, aspirations and plans that may be thwarted by an illness and its consequences. Furthermore, you will quite possibly face some changes in how you relate to yourself and in how other relate to you. A diagnosis may affect your self-esteem, and possible (but not unavoidable) changes to your body and body image may have a negative impact on your quality of life. You may need to change your daily routines and habits, too, which will also influence your immediate environment, i.e., your family and friends. You may also experience an increased degree of sympathy and pity from people around you, which may be welcome or burdensome.

The best way to cope with these changes is to spend some time considering what is it that you want. If you need more support, then say so to the people around you, and negotiate with them what you need and whether they can cover your changed needs. Also, be honest with yourself. You are not expected to either act as if you are not ill, or to solve every challenge alone. Asking for and accepting help is completely normal and human. If you feel that the burden of the illness is too much, seek professional help from a psychologist or psychiatrist. Patient organisations like MPE are also proficient in providing this type of support through their networks of peer helpers and professional counsellors. You are not alone on this journey and neither should you be.

Will I need to rely on a caregiver due to my condition?

Most AL amyloidosis patients can fulfil their daily living functions without help, meaning that you will probably not need to rely on a caregiver, at least not continuously. Generally, patients at more advanced stages of their disease, or patients undergoing intensive therapy, will need more support. However, you may need assistance in terms of accommodating changes in your life and to your body, which also includes psychosocial support. Chemotherapy and other treatment options may prove to be strenuous and exhausting. The periods of intensive treatment may require that you have some support, like someone who can drive you around or help out at home temporarily.

What kind of help and support might my caregiver need?

Caring for someone with AL amyloidosis can be a challenging experience, so it's important that caregivers receive the support they may need as well. As the responsibilities that may fall on someone caring for an AL amyloidosis patient could become overwhelming, caregivers might experience a lot of fear about losing their love one, and the unpredictability of the disease may further worsen their anxiety. Caring for a spouse or family member with AL amyloidosis might also mean having to take on additional work or housework and it can create financial strain if the patient has to quit working. We recommend that carers reach out to healthcare professionals, relatives, friends and voluntary organisations for additional help instead of letting themselves become overwhelmed. Caregivers should consider reaching out to counselling services for psychological support, too, or for help with practical matters and home help. Hospice services may also be available.

In addition, caregivers may have trouble finding the right way to communicate with the patient, especially about challenging topics (like those related to his or her illness). It is important to keep in mind that respectful open communication is always the best approach, although carers should not feel pressured to talk about everything right away - sometimes being there to listen may be sufficient. If a carer is struggling to discuss certain topics with the patient, involving a professional counsellor may be a good idea.

Can I exercise if I have AL amyloidosis?

Although every patient is different, some form of exercise may benefit you. Aerobic exercises (walking, cycling, using a cross trainer etc.) must be performed carefully, especially by patients with heart involvement. Exercise may reduce fatigue, feelings of anxiety and depression, and build muscle strength. If you are not used to regular physical activity, make sure you speak to your doctor in advance and then build up your routine gradually, while listening to your body and staying within your limits to avoid over-exhausting yourself. A visit to a physiotherapist, who can help to assemble an exercise routine that fits your needs and ability, may be beneficial. The key point to remember when exercising is not to overdo it and only do as much as you feel capable of. Stop exercising and consult your doctor if you experience dizziness or nausea, shortness of breath, or a sharp or stabbing pain in the chest, or any other area of your body.

When certain organs are affected by your disease, this may influence your ability to partake in certain forms of physical activity. Cardiac amyloidosis patients, for example, should take additional care during exercise, making sure that they stay below 80% of their maximum heart rate (which is defined by height, weight and age). If your immune system is weakened due to treatment side effects, you should take care to avoid places where you could easily contract an infection (e.g., saunas). It is also very important that you take care to minimise the risk of a

COVID-19 infection while exercising with people outside your household. If your doctor deems you healthy enough to receive the COVID-19 vaccine as well as the flu vaccine, we advise that you follow this recommendation. Furthermore, those around you, especially your carers, should receive their COVID-19 vaccine. This can lower the overall amount of virus spread and lower the risk of you becoming infected if your carer happens to catch COVID-19. This concept is known as "herd immunity". AL amyloidosis can cause bleeding, so sports should be avoided (e.g., contact sports) to minimise the chance of injuring yourself.

Does nutrition play a part in AL amyloidosis and its treatment?

It is important to follow a healthy diet as an AL amyloidosis patient. Your doctor or healthcare team may advise you on what to eat and drink, and what to avoid. Furthermore, following a special diet may lessen the effect of your disease on certain organs (for example, if amyloidosis affects the heart or kidneys, a low salt diet may be recommended).

What can I do to preserve my physical health and wellbeing beyond available treatment options?

There are no proven "alternative therapies" for AL amyloidosis. You are best advised to follow your doctor's recommendations and treatment plan. However, some general considerations also apply to this illness. Try to maintain a positive frame of mind despite all the adversity you are facing. Give yourself sufficient time to rest and recuperate; fatigue is a major issue for many AL amyloidosis patients, so getting plenty of sleep is a good idea. Pushing yourself might not help in this case - it is wiser to rest and pace yourself reasonably. Try to avoid putting your body under additional stress by consuming too much alcohol or any tobacco. Some exercise is beneficial, so try not to stay in bed all day long. Even if it seems difficult, staying active pays off in the long term – as with many other conditions, mild exercise yields much benefit. Many patients get regular, gentle foot or body massages to help with their fluid retention and fatigue.

Will AL amyloidosis influence my sexual and reproductive health?

Loss of interest in sex is not at all uncommon and may be caused by physical symptoms, for example, neuropathy caused by AL amyloidosis may lead to

erectile dysfunction. The psychological or emotional impact of your illness, such as feeling anxiety or exhaustion, may also affect your libido. Not wanting to engage in sex can lead to stress between partners. If having a sexual relationship is important to you and/or your partner, try to talk with him/her, so that you understand each other's feelings and ensure that neither of you misinterprets the situation. Try to find out together what level of physical contact feels right for the time being, and then gradually develop that into fuller intimacy when you are ready. Your doctors and nurses can also offer guidance and support. For example, if you suffer from erectile dysfunction due to physical reasons, your doctor can prescribe medications (such as sildenafil or tadalafil), which may be helpful. Furthermore, there are treatment options available for low libido for both genders, even though it is not common. For women, medications that increase libido (e.g., flibanserin, bremelanotide) or hormone therapy (e.g., oestrogen or testosterone) may be available. For men, topical (to be applied on the skin) testosterone may be prescribed.

Will the treatment affect my sexual and reproductive health?

Some treatment regimens are known to reduce libido, and some medications, for example, cyclophosphamide and melphalan, may affect fertility. The infertility that these medications may cause is often temporary, but could be permanent depending on which drugs you are given (e.g., high-dose melphalan and stem cell transplant) and what the dosage is. Permanent infertility is more likely with higher doses, like those given just before a stem cell transplant. It is important that you consult your doctor in case you are planning to have children in the future.

Your doctor may be able to refer you to a fertility specialist to discuss what can be done. It may be possible to undergo sperm or egg collection for later use, and fertility counsellors can provide supportive advice. In some countries, this may be reimbursed by the health care system and your doctor should also be able to give you information on this.

What can I do to preserve my mental health after I've received a diagnosis of AL amyloidosis?

All diagnoses are stressful, and this is also true for AL amyloidosis. At the same time, many patients report a sense of relief at receiving it after what sometimes

is a long process of tests and examinations to establish a diagnosis. Illness and its consequences are not your fault, and so try not to worsen your state by blaming yourself. If you find it very difficult to cope with, reach out to a patient organisation and ask for a consultation with a peer helper. Sharing your experience with someone who is in the same situation often helps with the feelings of helplessness, depression and the lows that come with the diagnosis and the disease. Usually, professional psychological help is also available in most healthcare settings and it may even be part of your medical team's offering (such as in the case of "onco-teams"). This kind of support may be reimbursed by the health care system in some countries and your doctor will be able to give you information on this.

Regular, gentle exercise, honest conversations with the people around you and a healthy diet all help with maintaining a good state of mind. Your mind and your body are one, so make sure that you don't neglect the health of either.

What is palliative care and when should I consider it?

Palliative care is specialised medical care for people living with a serious illness, which is focused on providing relief from the symptoms and stress of the illness. It is not the same as end-of-life care which is provided to people nearing the end of their life. The goal is to improve quality of life for both the patient and the family.

The Center to Advance Palliative Care uses the following definition: *"Palliative care is provided by a specially-trained team of doctors, nurses and other specialists, who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment."* When discussing how palliative care works, the Center states that *"palliative care teams are specialists who work together with you, your family and your other doctors. They provide an extra layer of support when you need it most. In addition to treating your symptoms and stress and supporting you and your family, the palliative care team communicates with all your doctors so that everyone is on the same page. They support you every step of the way."*

Your palliative care team can help with pain and other symptom (e.g., shortness of breath, vomiting and nausea) management, both by prescribing medication (such as opiates), by providing psychological support and by aiding consultation with the rest of your healthcare team. They can provide assistance for families to discuss sensitive issues, help to make medical treatment decisions, provide equipment needed to aid care at home, provide links to other services such as home help and financial support and give support with emotional, social and spiritual concerns.

MPE recommends that you consider palliative care services, if they are available in your healthcare system.

Where can I turn to for support and more information?

There are several useful resources available on the MPE website (for example, our AL amyloidosis guide and factsheets) and also follow MPE on our social media channels (Facebook, Twitter, YouTube) for regular updates related to myeloma and AL amyloidosis. It might be a good idea to join a local patient/advocacy group that represent amyloidosis patients (if one exists in your country) as it can be very helpful to form connections with others who are struggling with the same illness as you. Furthermore, you will gain access to valuable information about the disease and treatment options, which healthcare professionals to turn to, and self-caring and career suggestions etc. The group may host social events as well, and attending these can be a motivating, informative and positive experience. Examples of such groups are:

- Austria: Leben mit Amyloidose. www.amyloidosis-austria.at
- France: Association Française contre l'Amylose. https://amylose.asso.fr
- Germany: Amyloidose Selbshilfegruppe. www.amyloidose-selbsthilfe.de
- Israel: Amyloidosis Israel. www.amyloidosis.org.il
- Italy: Associazione Italiana contro leucemi limfomi e mieloma (AIL). www.ail.it
- Macedonia: Association for help and support of patients and their caregivers with hematological diseases (HEMA). www.hema.org.mk
- Netherlands: Stichting Amyloïdose Nederland (SAN). www.amyloidose.nl
- Norway: Blodkreftforeningenn. www.blodkreftforeningen.no
- Slovakia: Slovak Myeloma Society (SMyS). www.myelom.sk
- Slovenia: Association of Patients with Blood Diseases Slovenia www.drustvo-bkb.si
- Spain: Asociación Española de Amiloidosis (AMILO). www.amilo.es
- United Kingdom: Myeloma UK. www.myeloma.org.uk

Alternatively, you may consider reaching out to an umbrella organisation (like MPE) or other non-profit organisations that represent AL amyloidosis patients for support and information. Examples of such organisations are:

- Amyloidosis Alliance. www.amyloidosisalliance.org
- Amyloidosis Foundation. www.amyloidosis.org
- Amyloidosis Research Consortium. www.arci.org

References

1. AL - Amyloidosis Foundation.
2. My Battle with AL amyloidosis. Amyloidosis Foundation.
3. AL amyloidosis Matters Spring 2016, Myeloma UK.
4. Coronavirus disease (COVID-19): Herd immunity, lockdowns and COVID-19.
5. Frequently Asked Questions. Amyloidosis Patient Information Site.
6. Amyloidosis: Coping with Treatment | Cancer.Net.
7. Erectile dysfunction (ed) in patients with light-chain amyloidosis. EHA Library. Giordano C. Jun 9 2021; 324887.
8. Low sex drive in women. Diagnosis and treatment . Mayo Clinic.
9. Help for Low Libido in Men and Women . Sexual Health Center, Everyday Health.
10. Melphalan, Chemotherapy Drugs. Chemocare.
11. Cyclophosphamide: MedlinePlus Drug Information.
12. What is Palliative Care? Definition of Palliative Care. Get Palliative Care.
13. What is palliative care? Palliative Care Australia.

© Myeloma Patients Europe (MPE)

MPE is a network of European myeloma patient organisations. It supports national patient organisations to improve treatment and access for patients in their countries, and helps inform and raise awareness on a European level through its educational programmes. Please note, this information does not replace the information provided by your doctor. If there is anything that is not clear to you, please always ask your clinical team.

Myeloma Patients Europe

mpeurope
@mpeurope
Myeloma Patients Europe
info@mpeurope.org.
www.mpeurope.org

Q&A