

Finances

Living well with AL amyloidosis Infosheet

This Infosheet provides information about some of the potential financial challenges you may encounter as an AL amyloidosis patient and resources that may help, including benefits and allowances that may be available to you.

A diagnosis of AL amyloidosis can affect many areas of your life. In addition to concerns about your physical health, you may also find yourself experiencing unexpected financial concerns, if for example you have to stop working or reduce your hours because of your health.

Assessing your situation

A useful starting point is to assess your current financial situation. This can help to identify any potential

challenges your AL amyloidosis can have on your finances and what steps you may need to take. It may also be helpful to discuss your finances with an Independent Financial Advisor.

It is not possible to know exactly what will happen in the future and how it will affect you or your finances but taking sensible precautions and planning for a number of eventualities can help you alleviate some financial worry.

Work

Most financial worry for AL amyloidosis patients comes from having to reduce working hours or give up work and have a reduced income. It is likely that you will need to take some time off during treatment and/or periods of ill health. For some patients a change of job may be necessary, particularly if your work is strenuous and involves heavy manual labour, and some people decide that early retirement is necessary. Carers may also need to give up work or reduce their working hours.

It is normal to worry if you find yourself having to manage on a reduced income, but taking practical and sensible steps can help.

Pensions

If you have an occupational pension it may be worthwhile checking your entitlements under the scheme with your employer and if payments will be affected if your circumstances change e.g. if you are unable to work for a while or take early retirement. If you have a private pension it may help to discuss this with an independent financial adviser.

If you are considering early retirement on the grounds of ill health then you should discuss this with your doctor, your pension provider and/or human resources department at work.

Mortgages

If you do not have mortgage payment protection insurance and are experiencing financial difficulties then you should inform your mortgage lender as soon as possible. Sometimes it is possible to suspend payments for a short time, pay only the interest part of the mortgage or extend the term of your mortgage.

If the value of your house is much more than your outstanding mortgage then you may be able to remortgage your property

and release some money. If you are receiving Universal Credit, or certain other benefits, then you may be entitled to help with the interest part of your mortgage repayments.

If you are applying for a mortgage it is not always necessary to give your medical details. However, if life insurance or payment protection insurance are required then it is likely that you will have to give your full medical history.

Budgeting

Budgeting is key to managing your finances. It will make you aware of your income and expenses and how you can balance them to stay out of debt.

To start with, make a list of any regular income and assets that you may have e.g. savings accounts, investments, pension schemes, endowments and existing insurance policies. Then make a list of your regular outgoings and financial commitments including bills and debts.

Try to reduce any of your non-essential expenses, for example, by cutting out or cutting back what you do not need. If this doesn't balance the budget, you can try to reduce your essential outgoings by changing to a cheaper energy supplier, altering your mortgage payments or moving to a flat/house with lower rent. Keeping a spending diary can be useful to help you keep track of your money.

Debt

If financial problems mean that you are getting into increasing debt or you cannot pay off the debts you already have, it is important to seek help as soon as you can. Make sure that you are receiving all the

benefits and help you are entitled to by looking online at www.gov.uk, speaking to a social worker or going to your local Citizens Advice.

If possible try to deal first with any priority debts, e.g. outstanding mortgage or rent arrears and gas/electricity bills. If you are unable to keep up your payments, it is important to explain the reasons to your creditors – they may be prepared to accept reduced payments if they are aware of your circumstances. Further help regarding debt can be obtained from the National Debtline and from your local Citizens Advice.

Wills

You may want to update your Will, or make a Will if you do not already have one, to take into account any changes in your circumstances. It is advisable to discuss your situation with an independent financial adviser.

Some solicitors offer free will-writing services to support charities. Myeloma UK has a partnership with McClure Solicitors (www.mcclure-solicitors.co.uk) who will prepare and revise your will free of charge – with the opportunity to donate to Myeloma UK or leave a gift to the charity in your will, although there is no obligation to

do so. A list of regulated solicitors is also available on the law society website.

Travel insurance

Having a medical condition such as AL amyloidosis may make it more difficult or more expensive to get travel insurance, and it is important to read the “small print” of policies to make sure they are suitable for you. There are a number of insurance companies that specialise in providing travel insurance for people with pre-existing medical conditions.

For more information see the AL amyloidosis – [Travelling and Travel Insurance Infosheet](#) from Myeloma UK

Benefits

There are a number of different benefits and tax credits you may be able to claim:

- If you are aged over 16 and under the State Pension age you may be able to claim Personal Independence Payment
- If you are over the State Pension age and you have care needs, you may be able to claim Attendance Allowance

- If you are unable to work, you may be able to claim Statutory Sick Pay or Employment and Support Allowance
- If you care for someone who has AL amyloidosis, you may be able to claim Carer’s Allowance
- If you work, you may be entitled to Working Tax Credit or Universal Credit

Personal Independence Payment (PIP)

PIP can be claimed by people aged over 16 and under the State Pension age who have a health condition or disability which causes difficulty getting around or who need help with day-to-day living.

PIP has replaced Disability Living Allowance (DLA), so anyone claiming DLA will be contacted by the Department for Work and Pensions and asked to make

a new claim for PIP. Until you are contacted you will continue receiving DLA.

Attendance Allowance (AA)

This allowance is paid to people over the State Pension age and who have difficulty with personal care (e.g. washing, dressing, going to the toilet) and need help. AA does not cover mobility needs.

This allowance is tax-free and not means-tested and has two different rates depending on how much help you need.

Statutory Sick Pay (SSP)

If you are employed, earn at least £118 (before tax) a week and are unable to work because of ill health or disability then you may be entitled to SSP. SSP is paid by employers at a fixed rate of £94.25 a week for a maximum of 28 weeks. If you have contractual/occupational sick pay in the terms of your employment then you may be entitled to this as well as SSP.

Employment and Support Allowance (ESA)

ESA is for people who cannot work due to illness or disability and aren't getting Statutory Sick Pay. To claim ESA you will usually have to have various tests to confirm that you have limited capability for work.

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Carer's Allowance

If you are a carer and are caring for someone for at least 35 hours per week you may be entitled to Carer's Allowance.

The person you care for must be receiving a disability benefit e.g. Attendance Allowance or Personal Independence Payment.

Claiming Carer's Allowance may affect other benefits or

allowances that you or the person you are caring for claim.

Universal Credit

Universal Credit is a new benefit that will replace most means-tested benefits including:

- Income-based Jobseeker's Allowance (JSA)
- Income-related Employment and Support Allowance (ESA)
- Income Support
- Housing Benefit
- Working Tax Credit
- Child Tax Credit

Universal Credit is a single benefit which will be paid to people of working age. It was introduced in a very limited number of areas of the UK in April 2013 and is gradually

being introduced to the rest of the UK. The roll out for new claimants was completed in December 2018.

Since this time, rather than applying for the individual benefits that Universal Credit replaces, all new claimants have applied for Universal Credit.

If you haven't moved to Universal Credit and you are still on existing benefits or credits, the government plans to start transferring people from 2019 and have everyone transferred by 2023. Initially a small number of people are being transferred, and once this stage has been completed and assessed, more people will be transferred.

Carer's Credit

Carer's credit is a National Insurance contribution and enables carers to protect their State Pension. If you are unable to make full National Insurance contributions because you are caring for someone for at least 20 hours a week (and so you are not in work or you are working part-time), Carer's Credit can top up your contributions so you can still claim your State Pension when you reach State Pension age. You may be eligible for Carer's Credit if the person you are caring for is claiming AA or the middle or higher

rate of DLA. If you are claiming Carer's Allowance you will already be receiving Carer's Credit so you cannot apply for it separately. However, you may be eligible for Carer's Credit even if you are not eligible for Carer's Allowance.

These benefits are summarised in Table 1 on page 5.

Benefit/credit	Tax free	Means-tested	Age criteria	Work criteria	Caring criteria
Person Independence Payment	Yes	No	Over 16, below State Pension age	N/A	Need help with personal care or mobility
Disability Living Allowance	Yes	No	No new claimants over 16	N/A	Need help with personal care
Attendance Allowance	Yes	No	Over State Pension age	N/A	Need help with personal care
Statutory Sick Pay	No	No	Under State Pension age	Are employed but cannot work due to illness	N/A
Employment and Support Allowance	No	Yes	Under State Pension age	Disability affects how much you can work	N/A
Universal Credit	Yes	Yes	18 – State Pension age	N/A	N/A
Carer's Allowance	No	Yes	Over 16	Can work but must earn under £123 a week (after tax)	Care for at least 35 hours a week
Carer's Credit	N/A	No	16 – State Pension age	Not in work or working part-time	Care for at least 20 hours a week

What other benefits may I be entitled to?

You may be able to get other benefits as well, depending on your circumstances, for example Housing Benefit or benefits because you have children. You may also be able to claim Council Tax Reduction from your local council.

Other benefits you may be entitled to claim include:

Blue Badge scheme

The Blue Badge scheme allows people with severe mobility problems to park in parking-restricted areas. The Blue Badge enables badge holders to park close to where they need to go. The scheme operates throughout the UK; however, parking concessions may be different depending on where you live in UK.

Winter Fuel Payments

If you are over the state pension age, you might also be able to get a Winter Fuel Payment to help pay your gas and electricity bills during the winter months. This payment is paid directly into your bank account.

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Prescription charges

In Wales, Scotland and Northern Ireland all prescriptions are free of charge regardless of individual circumstances.

In England, you may be able to get free prescriptions in certain situations, including:

- If you are aged over 60
- If you have certain medical conditions (including cancer and hypoparathyroidism) and have a valid exemption certificate
- If you (or your partner) receive certain benefits

Your GP surgery or hospital clinic will be able to give you the form to apply for an exemption certificate (if you qualify for health reasons).

If you are not entitled to free prescriptions, buying a prescription prepayment

certificate (PPC) may save you money – you can apply either by calling the PPC order line on 0300 330 1341, or online at the

NHS Business Services Authority website www.nhsbsa.nhs.uk

VAT relief

If you have a long-term illness like myeloma, you will not be charged value added tax (VAT) on products designed or adapted for your personal use, or for repairs to such products. Both you and the supplier of the product will need to sign a declaration in order to obtain the VAT exemption. Details at www.gov.uk/financial-help-disabled/vat-relief

Further information and useful organisations

Blue Badge Scheme

www.gov.uk/get-blue-badge

England: 0343 100 1000

Northern Ireland: 0300 200 7818

Scotland: 0343 100 1001

Wales: 0343 100 1002

The Blue Badge Scheme helps you to park closer to your destination if you have mobility problems, whether you are a driver or a passenger.

Christians Against Poverty (CAP)

www.capuk.org

0800 328 0006

CAP provide free debt counselling to anyone worried about their finances through their local Debt Centres around the country. They can work with your creditors on your behalf to help you get out of debt.

Citizens Advice

www.citizensadvice.org.uk

England: 03444 111 444

Wales: 03444 77 20 20

Scotland and Northern Ireland: call your local Citizens Advice office

Citizens Advice offers advice about debt and consumer issues, benefits, housing, legal matters and employment. It provides assistance with claiming benefits, including practical help with filling out benefit application forms.

Information and advice can be accessed online, by telephone, and face to face at local Citizens Advice offices.

Gov.UK

www.gov.uk

The government website which provides information about a wide range of public services including benefits such as Attendance Allowance, Personal Independence Payments and Carer's Allowance.

You will find phone numbers listed to discuss the different benefits that are available.

Help with Health Costs

www.nhs.uk/Healthcosts

0300 330 1343

Help with Health Costs gives information about prescription charges and other help that patients can get with their health costs.

National Debtline

www.nationaldebtline.org

0808 808 4000

Offers free, confidential and independent advice on how to deal with debt problems in England, Wales or Scotland.

The Money Advice Service

www.moneyadviceservice.org.uk

0800 138 1677

The Money Advice Service is a free and impartial money advice service, set up by the government. It includes advice on insurance, benefits, debt and disability.

Unbiased

www.unbiased.co.uk

0800 023 6868

This is a directory of professional advisers which you can search or Unbiased can match you with a suitable adviser to give you

financial, mortgage, legal and accounting information. It is run by an independent non-profit body.

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your medical team. They are the people to ask if you have questions about your individual situation.

For a list of references used to develop our resources, visit myeloma.org.uk/references

To give feedback about this publication, email myelomauk@myeloma.org.uk

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We value your feedback about our patient information.

For a short online survey go to myeloma.org.uk/pifeedback or email comments to myelomauk@myeloma.org.uk

Other information available from Myeloma UK

Myeloma UK has a range of publications available covering all aspects of AL amyloidosis, its treatment and management. Download them from myeloma.org.uk/publications

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call the Myeloma UK Infoline on [0800 980 3332](tel:08009803332) or [1800 937 773](tel:1800937773) from Ireland. The Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK and Ireland.

Information and support about AL amyloidosis is also available around the clock at myeloma.org.uk/amyloidosis



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We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**

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