

Finances

This Infosheet provides information on some of the financial problems that you may encounter as an AL amyloidosis patient and provides resources for further help, including information on what benefits and allowances 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 worries.

If you are working it is likely that you may need to take some time off during treatment and/or periods of ill health.

Occasionally 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. If you are a carer then you may also have financial worries if you are unable to work and have to manage on a lower income.

This Infosheet aims to provide information on some of the more general financial problems that you may encounter, the benefits you may be entitled to claim, and provides resources for further help and advice.

Assessing your situation

A useful starting point might be to assess your current financial situation. This can help clarify things in your mind and will also be helpful if you go on to discuss your finances with a bank manager or financial advisor.

To begin 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 including debts and all other financial commitments that you may have.

The next step is to look for any way to increase your income or reduce your outgoings. Possible ways of doing this include: altering your mortgage payments, getting advice on debt management, checking eligibility for benefits, making any relevant insurance claims (e.g. if you have income protection, critical illness or private medical insurance) and,

in some cases, considering early retirement.

You may also 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 often advisable to discuss your situation with an independent financial advisor – see the details at the end of this Infosheet about how to find one.

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 Income Support or Universal Credit 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.

Pensions

If you have an occupational pension it may be worthwhile checking your entitlements under the scheme and whether 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 your financial position, needs and concerns 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.

Viatical settlement (also known as living benefit)

A viatical settlement is the name given to the transaction when an independent financial company buys an existing life insurance or endowment policy from a person who is not expected to live for longer than three years. This enables the person to have access to part of their policy value before they die.

If you are considering a viatical settlement then it is very important to discuss this with an independent financial adviser who will be able to advise you whether or not this is the best course of action.

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 speaking to a social worker or going to your local Citizens Advice Bureau Branch.

If possible try to deal first with any essential debts e.g. outstanding mortgage or rent arrears and gas/electricity bills. If you are unable to pay your bills then it is important to explain to your creditors the reasons why you cannot keep up any payments – 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 Bureau.

Benefits

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

- If you are aged 16 - 64 you may be able to claim Personal Independence Payment (or Disability Living Allowance in Northern Ireland)
- If you are 65 or over 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

Personal Independence Payment (PIP)

PIP can be claimed by people aged 16 - 64 who are very ill or disabled and have trouble getting around or need help with day-to-day living. It will eventually replace Disability Living Allowance.

Disability Living Allowance (DLA)

DLA is gradually being replaced by PIP. To get DLA, you must be under 65 and have personal care needs or difficulty with walking because of either a physical or mental disability. From 10 June 2013, in England, Wales and Scotland, you cannot make a new claim for Disability Living Allowance unless you are under 16; you must claim PIP.

If you're already getting DLA, your claim won't automatically be transferred to PIP - you'll have to make a new claim. However, you don't need to do anything about transferring your claim until the Department for Work and Pensions contacts you.

Attendance Allowance (AA)

This allowance is paid to people over 65 years old and who have difficulty with personal care (e.g. washing, dressing, going to the toilet) and need help. AA does not cover mobility problems. This allowance is tax-free and not means-tested and has two different rates depending on how much help and supervision is required.

Statutory Sick Pay (SSP)

If you are employed, earn at least £112 a week and are unable to work because of ill health or disability then your employer should pay you SSP. SSP is paid at a fixed rate of £88.45 a week. There is a standard rate of SSP and it is paid 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.

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 (PIP).

Other benefits, allowances or pensions you receive may affect your ability to collect Carer's Allowance. However, you are still encouraged to claim the allowance as you may still be eligible.

Working Tax Credit

This benefit can be claimed if you are disabled and work at least 16 hours a week. Working Tax Credit is paid by the HM Revenue and Customs, and depends on your income. It is paid in addition to benefits for the extra costs of disability such as Personal Independence Payment. However, Working Tax Credit may affect other income related benefits you get, for example, Housing Benefit.

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 if you are on a low income or benefits because you have children. You may also be able to claim Council Tax Reduction to help with your council tax.

Other benefits you may be entitled to claim include:

Blue Badge Scheme

The Blue Badge Scheme allows people with severe walking disabilities 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. Contact your local authority to apply.

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.

Prescription charges

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

In England, prescriptions are free for some patients (those with specified medical conditions, like cancer or hypoparathyroidism) on the production of an exemption certificate which can be obtained from GP surgeries or

hospital clinics. If you do not have an exemption certificate, buying a prescription prepayment certificate (PPC) may save you money – you can apply for a PPC by either calling the PPC order line on 0300 330 1341 or online at the NHS Business Services Authority www.nhsbsa.nhs.uk

For more information see the [Prescription charges Infosheet](#) from Myeloma UK.

To order your free copy call our Myeloma Infoline on 0800 980 3332.

This information is also available on our website at www.myeloma.org.uk

Universal Credit

Universal Credit is a new benefit that will replace many existing benefits. It was first introduced in April 2013 and has gradually been introduced throughout the UK. It is a single means-tested benefit which will be paid to people of working age. It 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 was introduced in a very limited number of areas of the UK in April 2013 and will be introduced to the rest of the UK gradually.

Further information and useful organisations

Blue Badge Scheme

www.gov.uk

England: 0844 463 0213

Northern Ireland: 0300 200 7818

Scotland: 0844 463 0214

Wales: 0844 463 0215

The Blue Badge Scheme provides a national arrangement of on-street parking concessions enabling people with severe walking difficulties who travel, either as drivers or passengers, to park close to their destinations.

Carer's Allowance Unit

0345 608 4321

General information about the carer's allowance, and assistance with filling in the application form.

Citizens Advice Bureau (CAB)

www.citizensadvice.org.uk

England: 03444 111 444

Wales: 03444 77 20 20

Scotland and Northern Ireland: call your local Bureau.

Citizens Advice Bureau offers advice about debt and consumer issues, benefits, housing, legal matters and employment. It provides assistance with claiming welfare benefits, including practical help with filling out benefit application forms. Check your local telephone directory for details of your nearest branch.

Gov.UK

www.gov.uk

A 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.

The Money Advice Service

www.moneyadviceservice.org.uk

0800 138 7777

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

Help with Health Costs

www.nhs.uk/Healthcosts

0300 330 1343

Help with Health Costs gives information about prescription charges and getting help with health costs, such as travelling to appointments, in England and Wales.

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.

Unbiased.co.uk

www.unbiased.co.uk

0330 100 0755

This is a directory of professional advisers which also, itself, provides 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. All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

Other information available from Myeloma UK

Myeloma UK provides a wide range of information covering all aspects of the treatment and management of AL amyloidosis.

For a full publication list visit www.myeloma.org.uk/publications

To order your free copies contact Myeloma UK. Our information is also available to download at www.myeloma.org.uk

To talk to one of our Myeloma Information Specialists about any aspect of AL amyloidosis, call the Myeloma Infoline on **0800 980 3332** or **1800 937 773** from Ireland.

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

Notes

Notes

Published by: Myeloma UK
Publication date: May 2009
Last updated: September 2016
Review date: September 2017

Myeloma UK 22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG
T: 0131 557 3332 **E: myelomauk@myeloma.org.uk** Charity No: SC 026116

Myeloma Infoline: 0800 980 3332 or
1800 937 773 from Ireland
www.myeloma.org.uk

Myeloma Awareness Week 21 - 28 June