

Home adaptations and living independently



KNOW YOUR RIGHTS
TOOLKIT



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Introduction

This toolkit is intended to be a short accessible guide to help you to explore your options if you are struggling to live independently or if your home is no longer suitable for you due to a diagnosis of a blood cancer. We understand that after a diagnosis of blood cancer, as it can impact every aspect of your life, and we are here to support you.

Whilst most people affected by blood cancers return to work after a diagnosis or after a period of treatment, others are affected by long term side effects. Blood cancer is also an illness most common in those over the age of 70, who may also have other illnesses that affect their day-to-day activities. Therefore, a blood cancer diagnosis or strong course of treatment may result in the need to adapt the home to allow

you to stay safe, healthy and independent.

If you are at immediate risk of homelessness, please read our [Homelessness Advice Toolkit](#) for additional advice. Homelessness is a serious hazard to your health, especially if you are unwell with a blood cancer, but it is preventable.

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Schemes and grants available to cover costs of adapting your home

I like my home and don't want to move but I am struggling due to health issues. Could my home be adapted?

If you are struggling with everyday tasks around the house as a result of your blood cancer symptoms or side effects and your home needs to be repaired, improved or adapted to cope, you may benefit from some specialist equipment or adaptation in your home. For example, you may be fatigued following treatment and struggle to use the stairs, or you may have pain in your joints that prevents you from being as mobile as you would like.

If you live in England, Wales or Northern Ireland, you may qualify for a Disabled Facilities Grant. These are available from your local authority to make your home more suitable, accessible, and secure and you

won't need to move.

You can request a home assessment, which is free, from your local authority. They will send an occupational therapist to your home to see what adaptations may help you and make recommendations. These may be big or small changes and include:

- Adding a bath lift, walk-in shower or grab rail
- Widening doorways
- Lowering kitchen worktops
- Fitting a stairlift or a banister on the stairs
- Putting in ramps for wheelchair access to the property
- Security, such as outside lights and intercom systems

Very often there is a long waiting list for a home assessment. You will need to complete an application form; our welfare officer can help you fill this in.

You might also be referred for a needs assessment to see if you could benefit from extra help at home, such as carers.

The amount of grant you get will depend on your household income and any savings you may have. Depending on your circumstances, you may be asked to contribute towards this cost.

In Scotland, the amount you get depends on what is recommended, your household income and savings. It will also depend on the cost of the changes to your property. You may be asked to pay something towards the cost, depending on your situation.

Emergency financial support

It is important that you keep your home warm whilst you are being treated for or recovering from intensive treatment for a blood cancer; therefore, you may

need to have some work done on the house quickly, such as if you are coming out of hospital and returning home. If you rent your house from a landlord, it is their responsibility to keep the house in order and you should approach them first.

Sometimes local councils offer emergency financial support for home adaptations or repairs, within their welfare assistance scheme. The support available is different for individual councils, but if you are experiencing a short-term crisis, such as a broken boiler, they may be able to help. It will depend on your situation and eligibility as to what financial support they can offer. For further information, contact your local council.

Home Improvement Agency

If you are struggling to live independently since your blood cancer diagnosis, you can

Schemes and grants available to cover costs of adapting your home (cont.)

also apply to your local home improvement agency (HIA) if you need assistance to repair, improve, maintain or adapt your home. The HIA consist of a network of not- for- profit organisations which has the sole aim of helping people live independently in their own homes. They may be able to help you find schemes to help with the cost of adaptations and also provide you with a list of trustworthy local builders and contractors. They offer specialist support and are funded by local and central government.

Local handyman service for small repairs

If you are blood cancer patient who is also over the age of 50, Age UK runs a local handyperson service over a large part of the country. They may be able to do small repairs, install grab rails and improve security in your home. These may be things that help you to feel more

comfortable and independent if you are returning home from hospital treatment or struggling with long term side effects. All individuals visiting anyone in their home are security-checked. Contact Age UK on **0800 678 1602** for further information.

Independence at home

This organisation is committed to supporting people of all ages with a disability or long-term illness. They may provide a grant for people in financial need towards the cost of improving your independence, comfort, safety and quality of life at home. You can contact them on **020 8427 7929**.

Grants

We understand that a diagnosis of blood cancer can result in financial difficulties, especially if you are not able to continue to work. This can make essential repairs or home adaptations difficult to pay for. There are a

number of charities or grant giving organisations that give out grants to those who are in need. Some have specific things that they will give grants for, whereas others are open to applications for anything that is needed by the applicant. These are often in high demand and go to those on the smallest incomes or otherwise deemed most in need first. The most well-known is the Macmillan grant for those affected by cancer, but there are many smaller organisations, often working at a local level, who may be able to assist. Again, this will depend on your situation, such as your income, savings etc. Most grant giving organisations require you to be referred by a welfare officer or similar professional; please get in touch with our welfare officer if you need further support.

Unsuitable housing

If the condition of your home is making it difficult to stay there, help may be available to make your home more suitable. This section will provide you with information about what you can do if your home isn't suitable.

I'm a social housing tenant, can I move to a different property?

If you are living in a property that is owned by the council or managed by a housing association but doesn't meet your needs because of the way your blood cancer affects you, you may be able to move to a different one. For example, if you are living in a second floor flat and have mobility issues due to the side effects of your treatment, they may be able to move you.

Depending on your circumstances you may want to consider applying to your local council to move into an empty home. If your council or housing association think you need to be given priority, you could be offered something sooner.

How can I exchange my home with someone else?

If your landlord is with the council or housing association and they have agreed that you can exchange, you will usually need to register with the council or housing association mutual exchange websites. Ask your landlord if there are any mutual exchange websites you can access.

For more information on moving or exchanging your home, please see our help with housing costs toolkit.

I am renting from a private landlord – can I apply for social housing instead?

Social housing may offer the chance to get a specific type of property that might be in short supply in the private market (e.g. if you have mobility issues since your blood cancer diagnosis and need a bungalow). You can contact the local council if you are eligible and ask to join the housing waiting list.

I need to move to a new house; what are my options?

If you are looking to move home due to the effect of your blood cancer symptoms and/or side effects, and your current home cannot be adapted, you may receive help to find a home more suitable to your needs.

Knowing when to move can be a difficult decision, especially if you have lived somewhere for many years. It may be a good option for you if:

- You have trouble getting in and out of your home, or moving around safely in your home, due to physical effects of your blood cancer diagnosis or treatment.
- You don't feel safe in your current house.
- Your home is too expensive (e.g. rent is too high), so you would struggle to stay even if it was made suitable with adaptations.

If you are thinking about moving there are many other options for you to consider, these include:

- Moving in with family

- Homeshare schemes
- Downsizing to a smaller property
- Sheltered housing
- Extra care housing
- Retirement villages
- Care homes

Homeshare schemes

This is where you share your home with another person. They are not paid to care for you, and you do not charge rent, but they share the household bills. The home sharer will help out by cooking meals and doing your shopping or other household chores. This option allows you to stay in your home and remain independent. It may be especially useful if you are affected by fatigue and need some support with day-to-day activities, but don't need formal care such as washing and dressing. It may also help if you feel isolated or lonely living alone; people who are diagnosed with blood cancer often report

I need to move to a new house; what are my options? (cont.)

feeling more isolated, so this could be a good solution if you do feel that way.

Sheltered Accommodation

Sheltered housing could be suitable for you if you want to live independently, need some support or if you want to live somewhere smaller and easier for you to manage. It is usually only available to those aged 55 and over and you have the freedom to come and go as you please.

Sheltered accommodation can be bought or rented. It can be paid out of your own funds, or if you meet the eligibility criteria you can apply to be allocated sheltered housing by your local council or housing association. As well as rent and/or mortgage payments, you have to pay council tax, water rates and energy bills and sometimes you will have to pay a service charge on top.

The type of house depends

on the scheme. Although it can vary, some schemes may include:

- 24-hour help through an alarm system within each property, so that you can call for help if you have a fall, for example.
- Help from a scheme manager or warden who will be able to advise and arrange for maintenance and repairs

A range of services and facilities will be offered at sheltered housing schemes. Whilst each scheme will vary, many will offer:

- Communal areas (such as gardens or a lounge) where residents can get together to socialise if they wish to.
- Entertainment and social activities, such as coffee mornings, bingo, bridge or quiz evenings
- Organised days out to places of interest
- Communal laundry (washers and dryers)

- Guest rooms so that family and friends can stay over

These services may charge an additional fee, so always check to find out.

Sheltered housing schemes do not offer any medical or nursing care, so if you require specific medical care, you may find that the better option would be a care home. However, this could be an option if you are worried about being isolated after a blood cancer diagnosis or want someone looking out for you in an emergency. If you are not sure what level of care you require, then you could request a needs assessment which can be carried out by your local authority who will be able define what care support you need. This is free of charge.

Extra Care Housing

Extra Care Housing offers more support than sheltered housing but still allows you to live independently. Again, this is only usually offered to those aged from 55-60 upwards. This

may be an option for you if you are left with physical disabilities following your blood cancer diagnosis or treatment, or if you struggle to care for yourself due to fatigue.

The communal services provided are often very similar to sheltered housing, listed above. Additionally, in extra care housing, staff are usually available to provide personal care and support services, up to 24 hours a day. You will have access to a self-contained flat with your own front door. Support given can include help with washing, dressing or help with shopping and laundry.

You may be able to buy or rent some extra care housing and some are available following a care needs assessment, but not available in every area.

Extra Care housing is regulated by the Care Quality Commission (CQC). They inspect the facilities and provide ratings.

I need to move to a new house; what are my options? (cont.)

Care Home

Moving into a care home is a big decision and it can cost a lot of money. It is worth considering all of your options. If after considering all of your options, you do decide a care home is the best place to meet your health and care needs, you will need to select which type of care home is right for you.

Further information

Call our Welfare Officer on **07903 219525** or email advocacy@leukaemiacare.org.uk for more information on topics covered in this toolkit.

Here are some additional resources who offer independent support and advice about housing related issues.

You can find your **local council's contact details** by visiting: www.gov.uk/find-local-council

To apply for a **disabled facilities grant**, in **England** and **Wales**, contact your local council or visit <https://www.gov.uk/disabled-facilities-grants>

In **Northern Ireland**, contact your local health and social care trust or visit the Housing Executive website at <https://www.nidirect.gov.uk/articles/disabled-facilities-grants>

In **Scotland**, contact your local council, call Care and Repair Scotland on **0141 2219879** or visit <https://www.mygov.scot/care-equipment-adaptations>

Find out if there is a **home improvement agency (HIA)** in your area on the following website: <https://www.findmyhia.org.uk>

You can see more information on **extra care housing** here: <https://www.ageuk.org.uk/information-advice/care/housing-options/assisted-living-and-extra-care-housing/>

For more detail on **care homes**, please visit **Age UK's** website here: <https://www.ageuk.org.uk/information-advice/care/arranging-care/care-homes/type-of-care-home/>

About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 9:00am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing support@leukaemicare.org.uk or over the phone on **08088 010 444**.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by

it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email support@leukaemiacare.org.uk

Online Forum

Our online forum, www.healthunlocked.com/leukaemia-care, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Webinars

Our webinars provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support. For information on upcoming webinars, go to www.leukaemiacare.org.uk/support-and-information/support-for-you/onlinewebinars/

Website

You can access up-to-date information on our website, www.leukaemiacare.org.uk.

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email advocacy@leukaemiacare.org.uk

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: www.leukaemiacare.org.uk/communication-preferences/

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk

advocacy@leukaemiacare.org.uk

Leukaemia Care,
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Worcester,
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Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).

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Leukaemia Care
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