

Living with Acute Myeloid Leukaemia (AML) - A Quick Guide



Contents

This is a brief summary of the information on 'Living with Acute Lymphoblastic Leukaemia (ALL)' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

- Coping with AML
- Sex, fertility and AML
- Diet and exercise after AML
- Life after transplant
- Questions for your doctor
- AML organisations

Coping with acute myeloid leukaemia

Coping with a diagnosis of cancer can be difficult, both practically and emotionally. It can be especially difficult with acute leukaemia because you often get ill suddenly, and have to start treatment quickly. There is usually very little time to take in information and start to cope with it. At first, you are likely to feel very upset, frightened and confused.

Coping practically with AML

As well as coping with how you feel emotionally, you will have to work out how to manage practically. There may be

money matters to sort out. Who do you tell that you have leukaemia? You may also have children to think about.

Remember you don't need to sort everything out at once. It may take some time to sort each issue. Do ask for help if you need it. Your doctor or nurse will be able to put you in touch with people specially trained in supporting people with cancer. For example, specialist nurses. These people are there to help, so use them if you feel you need to.

The 'coping with cancer' section of CancerHelp UK has lots of helpful information. There are sections on your feelings, helping yourself and how others can help you, sex and sexuality and financial support including information about benefits and sick pay, mortgages, pensions, loans and insurance.

Sex, fertility and acute myeloid leukaemia

Your sex life and AML

It is important to use contraception during treatment. Getting pregnant while you (or your partner) is having treatment is not a good idea, because the drugs might harm the baby. Even if you are taking the pill, you should use barrier contraception to make



sure your partner is safe. We don't think any of the drugs would get into your bodily fluids, but there is a small chance that they could.

Fertility after AML treatment

Most of the treatments for AML are likely to make you infertile. Permanent infertility is almost certain if you have more intensive treatment. Your doctor will tell you if it is likely you will become infertile. If you have a partner, you may want to see your doctor together so that you can both discuss any fears or worries.

Coping with infertility

It can be extremely distressing to find that your leukaemia treatment means you will not be able to have children. Even if you hadn't thought about having children before, losing your fertility can be very difficult to cope with. It can also affect how you feel about yourself. You need to give yourself time to feel sad and come to terms with it. Some people find it helpful to talk to a therapist or counsellor. Your doctor or nurse can put you in touch with professional help if you would like it. Don't be afraid to ask, as it really can help.

Diet and exercise after acute myeloid leukaemia

Diet and AML

Diet plays an important part in coping with cancer and its treatment. A good, well balanced diet can help you feel stronger, have more energy, and recover more quickly. While you are having treatment, you might have lost weight. If you still find it difficult to eat after your treatment has finished, you can try high calorie and high protein drinks. But you should begin to feel better and be able to eat a normal diet.

This can take a while after intensive treatment. Many people look at their diet and make changes, deciding to choose healthier options.

Exercise and AML

Exercise is a great way to help you feel better, both physically and emotionally. But don't overdo it. How much you can do will depend on how fit you are and how you feel. You will probably have days when you don't have so much energy. Listen to your body and build up slowly.

Gentle walking is suitable for most people to start with. Once your white blood count is back to normal and you don't have a central line anymore you can go swimming. Interestingly, taking regular exercise can help to reduce fatigue after treatment. Talk to your doctor if you aren't sure about how much you can do.

Life after transplant for acute myeloid leukaemia

It takes a long time to get over a bone marrow or stem cell transplant. It is not unusual to have to go back into hospital once or twice. And it may be a year before you really feel you are on the road to recovery.

Avoiding infection

To avoid infection for the first few months you will need to avoid undercooked eggs, soft cheeses, creamy cakes and puddings, and takeaways and fast food restaurants. Eat only freshly cooked foods, and wash salads and vegetables thoroughly. Avoid crowded places such as public transport. Keep away from anyone who has come into contact with an infectious disease such as chicken pox or measles.



School, college or work

You will not be able to get back to your usual daily life until your white cell count is almost normal. It is a good idea to go back to work or school part time at first. Talk to your employer, teacher or tutor about this. You may also want to think about whether you would like them to talk to your colleagues about your illness.

Sport and exercise

Exercise will help you to get your strength back. But while your platelet count is still low, you have to be careful about getting any knocks. Choose gentle exercise.

Holidays and travel

If you want to go abroad, talk to your doctors. They may want to contact a treatment centre near where you are going and let them know you are in the area.

Questions for your doctor about living with acute leukaemia

- How will my treatment affect me?
- Will I ever get back to normal, or will I have some long term side effects?
- Will I be able to go back to work / college / school?
- Is there anything I shouldn't eat?
- Where can I get help with claiming benefits and grants?
- What practical help is available?
- Why did this happen to me?
- Are my children at risk of getting cancer?
- Where can I get help in dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Could you refer me to a Macmillan nurse?

Leukaemia Organisations

Cancer Research UK
 Main website: www.cancerresearchuk.org
 Patient information website:
<http://cancerhelp.cancerresearchuk.org>
 Cancer Information Nurses phone: 020 7061 8355

Leukaemia and Lymphoma Research
 Telephone: 020 7405 0101
 Email: info@lrf.org.uk
 Website: www.beatbloodcancers.org
 Email: info@beatbloodcancers.org

Leukaemia CARE
 24 hour care line: 0800 169 6680
 Phone: 01905 755977
 Website: www.leukaemiacare.org.uk
 email: care@leukaemiacare.org.uk



Notes

More information

For more information about acute myeloid leukaemia, visit our website
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on
0808 800 4040 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in September 2010. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor.
© Cancer Research UK 2010 Cancer Research UK Charity Number 1089464