NHS
Royal Devon
University Healthcare
NHS Foundation Trust

Health and Well-Being Information and Support, after a blood cancer diagnosis. What next?

(Eastern services)

Other formats

If you need this leaflet in another format such as Braille, large print, high contrast, British Sign Language or translated into another language, contact the Patient Advice and Liaison Service:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Introduction

After being given a blood cancer diagnosis, it helps to know what to expect and how to access further information to get the best care and support for you. The Haematology Department in Exeter have developed this health and wellbeing leaflet for you, your family and your friends, outlining the things you can do to take control in a way that suits you.

Know your Cancer Nurse Specialist/Key Worker

You should be given the name and details of who to contact if you have any questions or concerns related to your cancer. This person is usually a **Cancer Nurse Specialist (CNS)** or **Cancer Support Worker (CSW),** sometimes referred to as a Key Worker. They will remain your contact providing clinical, physical and emotional support to you and your family throughout treatment and beyond. They will also be able to point you to services both inside and outside of the hospital environment. This may include healthcare professionals such as dietitians or physiotherapists or a local cancer support centre. In addition, your CNS/CSW will be able to liaise with both your cancer doctors and GP. This type of support is commonly referred to as ‘Personalised Care and Support’.

It is a good idea to write down the name of your CNS/CSW for future reference along with their contact details.

The name of my Cancer Nurse Specialist / Key Worker is: ……

Contact Details are:

01392 40 2879 / 07769882013

Raise your concerns and worries

After you are given a cancer diagnosis someone from your hospital team, usually your CNS/CSW, will talk to you about how you are feeling. This is known as a lifestyle and wellbeing conversation. You will usually be invited to an appointment and during or prior to this be asked to complete a checklist of any worries or concerns you may have (you may see this being called a holistic needs assessment). Your CNS/CSW will have a discussion with you and together you can look at possible strategies and produce a care plan. This may include giving you information leaflets, referral to other healthcare workers, and local or national cancer support organisations.

A lifestyle & wellbeing conversation will be offered to you just after receiving a diagnosis and a follow up appointment a couple of months later. You can request a further appointment at any other time. You can ask for a copy of the care plan so you are able to refer to it in the future.

You will also be invited to a health and wellbeing information & support clinic, which you should attend. This is run by a nurse specialist and cancer support worker. It is held in a small group setting and aims to provide information & resources to help you manage during treatment.

Make the most of your appointments

Attending an outpatient appointment can be a daunting experience. After the appointment you might realise you forgot to ask something, didn't understand what was said, or can't remember an answer. Healthcare workers can also at times use jargon or unfamiliar words, appointments can seem short and rushed, and you may feel unable to share physical, emotional or spiritual concerns as the healthcare workers look busy. Talking to us helps us to help you.

We recommend:

- Writing down questions you want to ask and bring them to your appointment
- It can also help to bring someone with you – they may recall information you have missed
- Try not to feel rushed and use your own words
- Let us know about any concerns or side affects you have without playing them down.
- Please ask for explanations in simple terms if you hear us use any 'jargon'.

Understand your cancer, symptoms and treatment effects

Haematology is the branch of medicine focusing on the study of the cause, prognosis, treatment and prevention of diseases related to blood. Haematological cancers are related to blood cells and the lymphatic system as opposed to the other body organs which would generally present as solid tumours and would be treated in the Oncology Department. The Haematology Department diagnoses, treats and cares for patients with blood cancers (and other diseases of the blood).

Some cancers have been found to be linked to lifestyle choices. For example, smoking has been found to increase risk of lung cancer. However, generally, no direct link has been found for haematology diseases and ongoing research into causes of cancers continues.

Cancer treatment will vary from one person to anotherYour treatment will be specifically prescribed for you depending on your type of cancer so timings, length of treatment and side effects can vary. Below are some of the treatment options you may be offered depending on your cancer type.

Systemic anti-cancer therapy

This can include chemotherapy and immunotherapy:

Chemotherapy – is usually a “systemic” (top to toe) treatment which aims to destroy cancer cells but also affects normal cells.

Immunotherapy – a treatment that stimulates your immune response to destroy cancer cells.

Radiotherapy – uses high energy x-rays to destroy cells in a specific area.

Clinical Trials – may be offered if appropriate for your stage and type of cancer.

Symptom Management – some treatments are given with the primary aim of controlling symptoms.

Having information about your cancer and what to expect can help you manage and plan from day to day. Ask your nurse or doctor for specific information leaflets which you can refer to. Finding out the expected side effects of your treatment can also help to allay anxiety. Knowing when to contact us can also be reassuring.

Understand your cancer, symptoms and treatment effects

As previously mentioned some cancer treatments may have side effects, these can vary greatly from person to person. The specific side effects for your individual treatment plan will be discussed in detail with you by your clinical team. It is important you let them know if you are experiencing any side effects.

You may like to:

- Ask us about your treatment plan e.g. what the aim of treatment is and how long treatment will last

- Ask for written information and a copy of your consent form. You may need to refer to this in the future
- You will be given a list of contact numbers for emergency advice on symptom control and side effects of treatment. You can find this in your cancer treatment record book
- Ask for information about clinical studies (research trials) that may be available to you.

Preparation of your treatment

How to manage fatigue and keep active

What is fatigue?

Fatigue is more than feeling a bit tired, it is an excessive lack of energy which can affect all aspects of life.

There is no easy answer for fatigue. However, we do advise trying a technique called energy conservation. Try thinking about your energy like a bank account and use the 3 P's, as shown in the diagram below to help.

Firstly – plan your day, when is that energy available to you? Get to know how much you have and when is it available to you, then.

Secondly - prioritise what you would like to do with it.

Lastly - pace yourself, listen to your body and rest before you get too tired.

The important thing is don't try using more energy than you have by keeping going as this may take you days to recover.

It is really important to look after yourself as fatigue can affect your emotions and your relationships so getting support is really important.

Let your clinical team know exactly how you are feeling so they are able to offer relevant advice.

Keeping active throughout cancer treatment and beyond

Exercise and moving around more is recommended during cancer treatment. The department of health recommends that we all do 150 minutes of moderate intensity (Moderate intensity means you should be slightly breathless but able to hold a conversation whilst you are walking, running or simply moving around more) exercise a week.

Please don't let this put you off we can break this down into manageable chunks for example 10 minutes in the morning and 10 minutes in the afternoon.

We all know that exercise can improve our mood, sleep and promotes a sense of well-being.

It can also help you to manage your fatigue as well as having benefits for your heart and lung function.

Sometimes it can be difficult to know where to start with exercise. We recommend you do something you enjoy so that you are more likely to keep going. Start slowly and gradually increase your activity levels. Don't forget you don't have to do long spells of exercise to make a difference, 10 minutes at a time is just as effective.

Here at the RDE and in collaboration with our local cancer charity FORCE, we have a wide range of exercise programmes to support you moving forward. These are available both within the hospital and your local community. Please ask your clinical nurse specialist for advice regarding the most appropriate service for you.

Diet and eating well

There is a lot of different and sometimes conflicting advice about diet and cancer. The general advice given by the NHS is a moderate and varied diet as demonstrated by “The Eatwell Plate” as demonstrated in the diagram below.

Following a healthy diet is important for all of us. However, we recognise that sometimes during treatment that may not be possible.

The Eatwell Plate suggests how what we eat would look like if you took all of the food that you eat over a week and put it on a large table. You can see about a third being starchy foods e.g. pasta/rice/potatoes. Another third would be fruits and vegetables. A small amount of proteins such as meat, fish, beans and eggs, an even smaller amount of dairy or dairy alternatives such as soya and a very small amount of oils and spreads. Don’t forget to drink plenty and keep treats as a treat.

We all know the benefits of eating well but during a cancer diagnosis it has the added benefit of improving treatment tolerance, it can also support recovery, healing and may reduce susceptibility to infections. However, for some people what you are able to eat during cancer treatment may need to change due to side effects of treatment such as pain, nausea, taste changes, difficult swallowing, chewing or fatigue. If you are having problems

with your eating, please contact your clinical nurse specialist who can refer you to a dietitian.

5 Top diet tips

- Eat at times when you are feeling your best even if this is not a normal mealtime
- If your appetite is reduced or you are losing weight use cream, cheese, oils and butter to boost calories within your meals
- Try something new, people often find that they like different foods, so try foods that you are drawn to even if they are new
- Ask for help - cooking can take valuable energy and for some people the smell puts them off eating.
- Make sure that you have some foods in the freezer or cupboard that you can make easily when you are feeling fatigued. e.g. tinned soup/baked beans or frozen meals.

Managing the emotional impact of a cancer diagnosis

Everybody deals with news of a cancer diagnosis differently, but in a way that is right for them. Feelings of uncertainty and fear of what the future might hold can be a response that many experience. Multiple hospital appointments, being told where to go and when can lead to a loss in confidence and confusion. Likewise, having concerns about our friends and family and how they might deal with the news can also increase your anxieties.

It can be helpful to think about how you have managed with difficult situations in the past and use some of those coping strategies. It can also be useful to know that our normal is very adjustable, so don’t expect too much at the moment and allow for that period of adjustment to take place.

Moving forward it is about finding the right balance for yourself, gathering support from family and friends is really helpful, but remember you don’t have to tell everyone it’s really up to you.

Try and maintain open conversations and let people know how you are feeling, if you are having a bad day say so, equally if it’s a good day let them know that as well without feeling guilty. Keep in mind the youngest people in your family and aim to give age appropriate information. This will help you to maintain an environment of trust, prevent unnecessary anxiety and prevent children from conjuring up a worst-case scenario. It can be useful to hold the conversation whilst you are doing something else such as: washing the dishes, walking or playing.

You may like to think about a friend or family member who might be able to help and support you. Where young children are involved, approaching the school/nursery can be really helpful, to make sure they are aware of the situation.

Please ask your CNS/CSW for further details.

Managing anxiety

Dealing with the here and now and noticing the good around you can really help.

Keep your expectations realistic. This is not the time to set marathon goals which will only disappoint you when not achieved and when in reality they were never achievable.

At this time support is available from your CNS/CSW please don't feel isolated and unable to talk to anyone.

We recognise that this can be a very worrying time. Consider writing worries down as a way of distracting yourself.

If worry becomes overwhelming, we would encourage you to talk to your CNS/CSW.

Family and friends

A cancer diagnosis can impact relationships with family and friends. There are several things you can do to help those you care about.

- Try to maintain open communication. This will help them feel less in the dark about what is going on and better able to support you
- Try to share with each other how you are feeling. It will help you feel more connected
- Let them know what practical help you need. Try to be honest about what is helpful or not
- Let them know that they can access support too.

Support and signposting

There are a variety of services available to support you, both in Exeter and Nationally, that you may find useful. We've listed some services below to help:

FORCE (Exeter Cancer Charity) Tel: 01392 406151

- Massage
- Relaxation & mindfulness classes
- Look Good Feel Better
- Acupuncture
- Exercise groups
- Financial advice
- Physiotherapy advice
- Yoga class
- Art class
- Moving forward after treatment workshop

- Living with non-curable cancer support

ELF (Exeter leukaemia fund): Tel: **01392 493344**

ElLFis a dedicated local charity for all people affected by a haematology diagnosis. They are available to help with transport to and from your Haematology hospital appointment.

ELF runs a counselling service available both to you and those supporting you.

KKLF (Kay Kendall leukaemia fund) – work in partnership with ELF to provide financial advice and support. They can help with benefit applications, blue badges or any other concerns you may have around finances and work. Tel: **01752 507711**

Alternative support services

- Macmillan Cancer Support
- Myeloma UK
- Lymphoma Action
- Leukaemia Care
- Patient Advice and Liaison Service (PALS), onsite at RDE
- Shine Cancer Support (Supporting adults aged 20-40).
- Defence Medical Welfare Service (DMWS) (Supporting veterans/ immediate family members)
- Hospice care
- Local Libraries, Community Centres, Gyms, Health Centres
- Red Cross, Age Concern, local charities

Finances and cancer

Work

Having a cancer diagnosis means you are protected under the Equality Act 2010 and the Disability Discrimination Act 1995

If you are working we advise you to open up a conversation with your employer or occupation health department. If you require additional support or advice this can be offered through the citizens' advice bureau (CAB). The 'Kay Kendall Leukaemia Fund' CAB has supportive advisors to help with financial concerns and advice. Please ask your CNS/CSW for their contact details. In addition, Macmillan Cancer Support has an online service which includes financial grants. Please keep in mind some of these are means tested. Your CNS/CSW can help you to arrange this.

Car travel

Requiring extra travel to and from the hospital can prove costly. If you have more than 3 trips per week you may be entitled to NHS supported transport, please ask your CNS/CSW.

The ELF charity has a fleet of cars with friendly and reliable drivers dedicated to picking up haematology patients for their appointments and taking them back home again. Please liaise with your CNS or clinical team for more information and booking. If you are already receiving benefits or pension credit we may be able to refund travel through our general office but please keep receipts. Parking payment exemptions are provided free of charge if you are receiving chemotherapy or radiotherapy. Please ask at the relevant reception areas when arriving for your treatment.

Prescriptions

Prescriptions are free of charge for the five years following a cancer diagnosis, please visit your GP for an exemption certificate.

Hair loss and wig fitting

To help support with hair loss a wig fitting service is available every Wednesday through FORCE. Your clinical team will discuss with you whether your prescribed treatment may potentially result in hair loss or hair thinning and your CNS/CSW will complete a wig prescription to enable you to access support through FORCE.

There is a charge associated with this prescription, however, if you are already receiving benefits please let the staff know as this fee will not apply.

Once a prescription has been completed contact the appliance officer (Tel: **01392 402128**). They will check your details, issue you with an order number and provide you with the number to call to book an appointment with Natural Image or Browns More Hair Now. In addition to wigs there is an excellent selection of fashion scarves available through FORCE.

Travel insurance

Following a cancer diagnosis travel insurance can be costly. Your doctor can provide you with a certificate saying you are fit to travel but there may be a fee for this, please ask at your GP practice. Try contacting your usual insurer but if the cost is too high please contact the FORCE centre or the Macmillan website.

Shopping around for a better premium can be beneficial and sometimes insuring per trip rather than taking out an annual policy will be cheaper.

After cancer treatment finishes, what next?

Usually there is a time of adjustment following completion of your treatment. Supportive/ maintenance treatments may be ongoing for some time. If you have any concerns during this time please contact your CNS/CSW for continued support.

How you will be followed up will be discussed with you individually. This may include coming back to the outpatient department, via telephone calls, visiting the hospital for scans or tests or by blood tests at your GP's. Details of your treatment, your follow-up and what to look out for will be included in a **Treatment Summary** which will be posted to you and your GP.

Approximately six months following your diagnosis you are entitled to a **Cancer Care Review** with your GP. This provides a further opportunity to let a Health Care Professional know how you are feeling. Please make an appointment at your GP's if you wish to have this.

Support through FORCE is available for two years following your diagnosis. In addition, you are also welcome to contact online services such as Macmillan or Cancer Research UK.

We hope you have found the information in this leaflet helpful.

Your health & wellbeing appointments

- Lifestyle & wellbeing appointment 1: ……....
- Lifestyle & wellbeing appointment 2: ……....
- Health Wellbeing Information & Support Clinic: ……

Your notes

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern, please contact PALS:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Have your say

Royal Devon University Healthcare NHS Foundation Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

You can also share your feedback on the Care Opinion website at www.careopinion.org.uk or freephone 0800 122 3135.

Scan the QR code to visit the Care Opinion website →

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