NHS
Royal Devon
University Healthcare
NHS Foundation Trust

Taking control after a cancer diagnosis – six things you can do

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 cancer diagnosis, it helps to know what to expect and how to get further information to get the care and support best suited for you. We have developed this leaflet to let you, your family, and your friends know of six things you can do to take control in a way that suits you.

1. Know your clinical nurse specialist/keyworker

You should be given the name and details of whom to contact if you have any questions or concerns related to your cancer. The person is usually a clinical nurse specialist (CNS) or cancer support worker (CSW) (keyworker). They will be your contact throughout your treatment, providing advice and support which may include signposting to services both inside and outside of the hospital environment. This may be FORCE, the Fern Centre, ELF, or Hospiscare, our local cancer support charities/centres, national charities, Macmillan or Cancer Research UK, or other healthcare professionals such as physiotherapists, dietitians, speech and language therapists, or occupational therapists.

The name of my CNS/CSW (keyworker) is: .....

Contact details are: .....

My oncologist/surgeon's name is .....

My diagnosis is .....

Your notes

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2. Raise you concerns and worries

When you are given a cancer diagnosis, someone from your healthcare team, usually your CNS/CSW, will talk to you about how you are feeling. You may be asked to complete a lifestyle and wellbeing concerns checklist. This is a simple set of questions which offers you the chance to let us know about any worries or concerns you have. The questions may be answered on paper or electronically through your MyChart portal. Your CNS/CSW will have a discussion with you and together you will be able to look at possible solutions and produce a personalised care and support care plan which may include giving you information leaflets, or referring you to other healthcare workers or local/national cancer support organisations.

You can:

- Ask for a lifestyle and wellbeing concerns checklist if you have not yet received one
- Ask for a copy of the personalised care and support care plan so you can refer to it in the future
- Make a list of things you would like to talk about, including what matters to you most.

Your notes

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3. Understand your cancer, symptoms and treatment effects

Having information about your cancer and what to expect can help you manage and plan from day to day. Ask your CNS or doctor for specific information leaflets which you can refer to. Ask us about the expected side effects of your treatment, this may help to allay any anxiety. In addition, knowing when to contact us can also be reassuring.

You can:

- Ask us about your treatment plan, e.g. what is the aim of your treatment and how long the treatment will last
- Ask for written information and a written care plan about your treatment. You may need to refer to this in the future.
- Attend a health and wellbeing information and support clinic/fair (information/education session). This is a chance to get information on practical, social, emotional and financial topics.
- Keep a list of contact numbers for emergency advice on symptom control and side effects of treatment
- Ask for information about clinical studies (research trials) that may be available to you.

Your notes

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4. Make the most of your appointments

Attending an outpatient appointment can be a daunting experience. It is often after the appointment that you realise you have forgotten to ask something, didn't understand what was said, or can't remember an answer. Healthcare workers can 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 if the healthcare worker looks busy. Talking to us helps us to help you.

To help make the most of your appointments, you can:

- Write down questions you want to ask beforehand and bring them to your appointment

- Bring someone with you. They may recall information you have missed and can also write down the answers to your questions.
- Try not to feel rushed and use your own words
- Let us know about any side effects or concerns you have without playing them down
- Ask for explanations in simple terms.

Your notes

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5. Explore your options for keeping well, both now and in the future

Looking after your health and wellbeing is important. Making small changes with what you can do to help yourself can make you feel good.

You can also:

- Access health and wellbeing information and support by attending a clinic or fair offered to you
- Ask your CNS if it's appropriate for you to be referred to a physiotherapist
- Use local libraries and information centres to find out what's on offer in your local area, such as 'walking for health'
- Ask your CNS if it's appropriate for you to be referred to a cancer dietician
- Make an appointment for a cancer care review with your GP three months after your cancer diagnosis.

Your notes

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6. Getting help and support

It is really important to accept and build support around you at this time. People often tell us how they feel lonely and isolated after a cancer diagnosis. For some it can be difficult to open up a conversation and share their worries with loved ones as they feel they will upset them. However, silence can make you feel more isolated, so if you are struggling please get help.

It may help to:

- Try and maintain open conversations
- Have conversations whilst doing something else
- Don’t be afraid to ask for support – talk to your CNS
- Contact our local charities who offer counselling and can give guidance on how to open the conversation. This support is free and available for up to two years following your diagnosis.
- Consider local support groups – ask your CNS for information.

Your notes

Questions for your clinic appointment

Questions for your clinic appointment

Help available

Our **CNSs and CSWs** are all skilled communicators and receive additional training to support you. They will have an in-depth knowledge of your specific cancer, its treatments, and side effects. We also have a specialist physiotherapist and dietitian who can support you with a range of groups and 1:1 service.

Exeter Leukaemia Fund (ELF)

ELF offers free face-to-face and phone support to blood cancer patients and their families, offering services such as counselling, complementary therapies, transport services, information and advice, and support with legal services. We are based on the haematology unit at the Royal Devon's Wonford site and have a suite of accommodation rooms available. Please feel free to drop in to access information and support or have a chat with one of our volunteers.

ELF
Phone no: 01392 493344

FORCE

FORCE offers free face-to-face, phone, and online support to cancer patients and their families, offering services such as counselling, complementary therapies, support groups, financial and benefits advice, exercise advice, and an information helpline with a team of nurses and advisors. We are based at the Royal Devon's Wonford site and have outreach hubs at Okehampton, Tiverton, and Ottery St. Mary. Please feel free to drop in to access information or have a chat with one of our volunteers.

FORCE Support and Information Centre
Information and advice: 01392 406151
Psychological and emotional support: 01392 406168 / 406169

Fern Centre

The Fern Centre offers free face-to-face and phone support to cancer patients and their families, offering services such as counselling, complementary therapies, support groups, and financial and benefits advice. We are based at the Royal Devon's NDDH site and have outreach hubs at Holsworthy and Ilfracombe. We also have three en suite accommodation rooms available to relatives of patients being cared for in the hospital. Please feel free to drop in to access information or have a chat with one of our volunteers

Fern Centre
Phone no: 01271 311 855

Macmillan

Macmillan offers online and phone-based information and support, and a chance to share and learn from others in its online community. They also host a range of patient

information booklets on the topics in this patient leaflet, which you are able order or view at your local cancer centre.

Macmillan cancer support
Phone no: 0808 808 00 00

If you want to know more about other organisations who may be able to support you, for example LGBTQI+, disabilities, or charities specific to your cancer, talk to your CNS or CSW.

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 →

Royal Devon University Healthcare NHS Foundation Trust
www.royaldevon.nhs.uk

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www.royaldevon.nhs.uk/get-in-touch