A practical guide to living with and after cancer

WE ARE MACMILLAN CANCER SUPPORT

HOLISTIC NEEDS ASSESSMENT

Planning your care and support
About this leaflet

Being diagnosed with cancer can affect many areas of your life. This is why you may be offered a Holistic Needs Assessment (HNA).

This leaflet covers:

• what an HNA is
• what issues you may wish to discuss
• how to prepare for the assessment
• what your care plan will include and who it will be shared with.

Throughout this leaflet we’ve included quotes from people affected by cancer who have had an HNA. They have chosen to share their story with us through macmillan.org.uk/cancerv voices
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What is an HNA?

A Holistic Needs Assessment (HNA) gives you a chance to think about your concerns and discuss possible solutions.

It is called ‘holistic’ because the assessment looks at needs or concerns you may have about any area of your life. It isn’t just about looking at the symptoms of the cancer.

These concerns can be:

• physical
• emotional
• practical
• financial
• spiritual.

You will talk about these with your key worker and make a plan to address your care and support needs. Your key worker is your main contact for information and advice about your treatment. This is usually your clinical nurse specialist (CNS).

Having an HNA is about recognising that any area of your life affected by cancer is important. It gives you the time to explore what resources, help and support are available.

We have a video called The Recovery Package which has more information about the HNA. You can watch it at macmillan.org.uk/recoverypackage
An electronic Holistic Needs Assessment
What happens at an HNA?

An HNA usually has three parts:

1. **You answer a simple set of questions or fill in a checklist about all areas of your life.**
   This is to identify any concerns you may have. You are often asked to rate how mild or severe your concerns are. This can help decide what needs to be dealt with first. You may answer the questions on paper or on an electronic device, such as a tablet (see the picture on page 4). It usually takes under ten minutes to complete.

2. **You discuss answers with your key worker.**
   This is a chance to talk about the issues you have identified. You can bring a carer, family member or friend to this meeting.

3. **You create a care plan together.**
   You will then discuss and plan how to deal with your concerns. This is sometimes called a care plan.

The care plan may include ideas to help you manage emotional, physical or practical worries. It will also include contact details for organisations or services that could help with your concerns, such as the Macmillan benefits team or a dietitian. For more details about care plans, see pages 13 to 14.

Your key worker will write down the actions you have agreed. You will then be given a copy of the plan to take away with you. It may also be shared with other members of your healthcare team if it will help with your care.
What is an HNA?

Discuss answers with a health professional

Create a plan together

What are the benefits of having an HNA?

• You can get information and support for any symptoms or concerns you may have.

• It can help you prioritise your most important concerns.

• It can help your key worker understand what is important to you.

• Your key worker can refer you to other services, if this would help.

• You can find out about support groups in your area.

• It can help you plan ahead – from diagnosis through to treatment and life after treatment.

1. Fill in a checklist

2. Discuss answers with a health professional

3. Create a plan together
When does the assessment happen?

You may be offered an HNA around the time of your diagnosis, during treatment or after treatment has ended. If an assessment is not offered, you can ask your key worker for it. Because your needs may change, you can ask for an assessment at any time if you feel it would help.

You may have a separate appointment for the HNA, or it may happen at the same time as your other appointments.

You may be sent the checklist of questions before the appointment. Or you may be asked to fill out the checklist in the waiting room before you meet with your key worker. Help will be available if you need it.

‘It’s a really good prompt. When you’re looking at the iPad you can just tick a box, and then they can go through it with you.’

Tracy
Who do I have the assessment with?

You will talk about your answers to the checklist with your key worker or another member of your healthcare team.

Whoever you speak to should have the skills and experience to help identify and discuss your concerns. They should have up to date knowledge of local and national services, and know how to refer you to additional services if you need them.

Tell your key worker if you would like a family member or friend with you for the discussion. If you have a **carer**, they can come with you to talk about their concerns too. A carer is someone who provides unpaid support to you, which you could not manage without. However, the assessment is mainly designed to focus on your needs and concerns. You can also ask for an interpreter if you need one.
How long will the assessment take?

For many people, the assessment takes about 30 minutes. You may feel there won’t be enough time to talk about some of your concerns or that they are not important enough to mention. But the HNA should take as long as you need to talk about your main concerns.

If there are still issues you want to talk about at the end of the assessment, your key worker can make another appointment with you.

Where will the assessment take place?

The assessment should be held in a private and comfortable setting. If it is with your key worker, it will usually take place where you have your treatment or care, for example at the hospital or health centre. The assessment may also happen over the telephone. The options will be explained by your healthcare team. You should tell your key worker what you would prefer.
Discussing your care

These are your concerns, so it is up to you what you talk about in the assessment. You may want to discuss concerns such as:

- physical symptoms (such as weight loss, problems with appetite or eating, and tiredness)
- treatment issues (such as side effects, fertility, and the risks and benefits of treatment)
- emotional concerns (such as worries about the future and relationships)
- sexual concerns (such as erectile dysfunction or loss of sex drive)
- family matters (such as talking about the cancer, and worries about genetic risk to other family members)
- job, money or housing worries (such as balancing work and treatment, and benefits or financial advice)
- practical issues (such as sorting out housework, and where to get equipment that can help)
- spirituality (such as your faith or beliefs, and any impact this may have on your treatment).

The suggestions on the next page may also help you decide what you would like to discuss.

We have booklets and leaflets about the physical, emotional, practical and financial effects of cancer and what may help. Call 0808 808 00 00 or visit be.macmillan.org.uk to order free copies.
Preparing for your discussion

To get ready for the discussion, some people find it helpful to make notes of any concerns or questions they have in advance. You can use the space on page 17 to write down your notes.

You may want to think about these questions:

- Is anything bothering you about your relationships with family or friends that could be related to the cancer?
- Are your family and friends coping with knowing you have cancer?
- Would you like to know about local services, support groups or helplines?
- Do you need advice about diet, being physically active or stopping smoking?
- Are you confused by any part of your treatment or follow-up care? Is there anything you would like explained?
- Do you need help with finances, work or education?
- Are you worried about the future?
- Do you feel your quality of life could be improved?
- Are you having any symptoms or side effects from the cancer or treatment?
- Do you know what signs and symptoms to look for and who to contact if you notice any of them?
- Do you know who to contact if you have any problems (for example, do you have the contact details of your key worker)?
Discussing your care

These are suggestions. Not all of them may be relevant to you. The assessment is about your personal concerns, so you can tailor the discussion to your situation.

‘It’s not always just cancer problems. It’s things that affect your work or your family life, or your relationships with your friends.’

Jane

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country. You can find more information at macmillan.org.uk/cancerregistry
Your care plan

During the discussion, you will agree with your key worker the best ways to manage your concerns. These actions are put into a document called a care plan. Sometimes this is called a support plan.

Your care plan will record:

• the main concerns you talked about during the discussion
• suggestions and actions to help you manage your concerns
• services that may be able to support you and any referrals that were made
• what is already being done to help, or services you are using
• information about who to contact if you need more help
• which other health or social care professionals you have agreed to share the information with.

You should be given a copy of the care plan. Your key worker may write the plan during the discussion, or make notes and send it to you afterwards. You can request another copy from your key worker at any time.
A copy of the care plan may be sent or given to:

• your GP, so they know your concerns and what help is planned
• other members of your healthcare team, to help them plan or improve your care
• specialist support services (such as a dietitian, counsellor, benefits adviser or family support worker).

Your key worker will only share your care plan with your permission. They will only share as much information as people need to know for their role in your care.

Your care plan will be securely stored electronically or as a paper copy along with your other health records. You can ask your key worker for a review of your care plan or a new assessment at any time.
Further information and support

Cancer is the toughest fight most of us will ever face. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

Macmillan Cancer Support
89 Albert Embankment, London SE1 7UQ
Tel 0808 808 00 00
(Mon to Fri, 9am to 8pm)

Hard of hearing?
Use textphone 0808 808 0121, or Text Relay.

Non-English speaker?
Interpreters are available. Alternatively, visit macmillan.org.uk

To order any of our booklets, visit be.macmillan.org.uk or call us on 0808 808 00 00.

Macmillan Cancer Voices
www.macmillan.org.uk/cancervvoices
A UK-wide network that enables people who have or have had cancer, and those close to them, to speak out about their experience of cancer.

Other useful organisations

Cancer Research UK Helpline
0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.
Further information and support

Health and Social Care in Northern Ireland
www.hscni.net
Provides information about health and social care services in Northern Ireland.

Healthtalk
Email
info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-people-experiences (site for young people)
Has information about cancer, and videos and audio clips of people’s experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS Choices
www.nhs.uk
The UK’s biggest health information website. Has service information for England.

NHS Direct Wales
www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform
Helpline
0800 22 44 88 (Daily, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK
www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.
Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This leaflet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Timothy Iveson, Macmillan Consultant Medical Oncologist.

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Sources

We’ve listed a sample of the sources used in this leaflet below.

If you’d like further information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk


This leaflet is about the Holistic Needs Assessment (HNA), which helps plan your care and support following a cancer diagnosis and during treatment.

It explains what an HNA is, what it covers and how you can prepare so that you can get the most out of the assessment.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, Monday to Friday, 9am to 8pm, or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit macmillan.org.uk/otherformats or call our support line.