MACMILLAN CANCER SUPPORT

HOLISTIC NEEDS ASSESSMENT

Planning your care and support



About this leaflet

This leaflet is about a Holistic Needs Assessment (HNA). An HNA identifies any concerns you may have when you have been diagnosed with cancer. These concerns may be physical, emotional, practical, financial and spiritual.

The leaflet explains what happens at an HNA and has information about making a care plan. It is for anyone who has been diagnosed with cancer.

We hope it helps you deal with some of the questions or feelings you may have.

Quotes

In this leaflet, we have included quotes from people who have had an HNA. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment 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 to opt out.

Contents

What is an HNA?	4
What happens at an HNA?	5
What are the benefits of having an HNA?	6
Who do I have the HNA with?	7
When does the HNA happen?	8
Where will the HNA happen?	9
How long will the HNA take?	10
Discussing your care	11
Further information	16
Other ways we can help you	17
Other useful organisations	19
Your notes and questions	23

What is an HNA?

A Holistic Needs Assessment (HNA) is an assessment and discussion you may have with someone from your healthcare team. Together, you talk through your needs and concerns. You then agree on a plan for your care and support needs.

It is called holistic because you can discuss any needs or concerns you have about any area of your life. It is not only about the physical symptoms of cancer or the side effects of treatment.

These concerns can be:

- physical
- emotional
- practical
- financial
- spiritual.

HNAs may not be standard practice in all hospitals. The HNA may happen in the ways we describe in this leaflet, or it may be more informal. If you are not offered an HNA and would like one, you can ask someone from your healthcare team about it.

In the first consultation I usually do an HNA where we can talk about their care beyond just treatment, and identify any unmet needs.

Alexandra, Macmillan Review Radiographer

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 find out about the concerns you may have. You are often asked to rate how important these concerns are to you. This can help you decide what to discuss first during the assessment.

2 – You discuss your answers with someone from your healthcare team. This is a chance to talk about the issues that are most important to you.

3 – You create a care plan together for managing your concerns.
This is sometimes called a personalised care and support plan.
If there are simple ways to help you, you may not need a written care plan.

What are the benefits of having an HNA?

- You can get information and support to help you manage your concerns.
- It can help you identify the concerns that are most important to you.
- It can help your healthcare team understand what is important to you.
- You can be referred to other services if you need more help or support.
- You can find out about local support groups.
- It can help you plan ahead.

The HNA means I can look after patients and their families as a whole – not just the radiotherapy part of their cancer journey but also looking at other areas where I can offer support.

Alexandra, Macmillan Review Radiographer

Who do I have the HNA with?

You have the HNA with someone from your healthcare team, usually your key worker. Sometimes you have it with a cancer support worker who works alongside them. Your key worker is usually your clinical nurse specialist (CNS) or another member of your healthcare team. They are your main contact for information and advice. If you have not been given a key worker, ask your cancer doctor or GP about who can do the HNA with you.

Your key worker has the skills and experience to help you identify your needs and talk about them with you. They also have up-to-date knowledge of local and national services. They can refer you to other support services you may need. They may print out some Macmillan information to give to you.

If you are having a face-to-face assessment, you can bring a family member, carer or friend with you. You can ask for an interpreter if you need one.

When does the HNA happen?

You may be offered an HNA around the time when you are diagnosed, during treatment or after treatment has ended. If you are not offered an HNA, you can ask someone from your healthcare team to arrange one for you. Because your needs may change, you can ask for another HNA at any time.

You may have a separate appointment for the HNA. Or it may happen at the same time as one of your other appointments.

You may be sent the checklist of questions to do before the HNA. Or you may be asked to do it in the waiting room beforehand. The checklist may be a paper copy or on a handheld electronic device (tablet). If it is done on a tablet, it is called an EHNA. If you need help answering the questions, tell your key worker.

Where will the HNA happen?

The HNA should be done in a private and comfortable room. If you have it with your key worker, this is usually at the hospital or health centre. Sometimes it may happen over the phone.

After my treatment was over, my breast care nurse did an HNA. It identified various clinical and non-clinical needs where having support would help my recovery. It highlighted my fatigue and also problems dealing with my emotions.

Elaine

How long will the HNA take?

The HNA usually takes about 30 minutes. Some people may need longer. It should take as long as you need to talk about your concerns. If there are still some things you want to talk about after it has finished, tell your key worker. They can make another appointment with you.



Discussing your care

What the discussion may include

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

- Your physical symptoms such as pain, tiredness, bowel or bladder problems, and weight changes.
- Your treatment such as side effects, fertility and the risks and benefits of treatment.
- Your emotions for example, fear of cancer coming back or the effect of cancer on your relationships.
- Your sexual well-being such as concerns about intimacy, getting an erection or low sex drive.
- Your family such as how to talk about cancer, or whether your family are at risk of getting it.
- Your well-being after treatment for example, giving up smoking, eating healthily or staying active.
- Follow-up appointments, tests you may need and knowing what symptoms to look out for.
- Work, money and housing for example, advice about working during treatment, benefits and financial help
- Practical issues such as how to manage housework and where to get aids and equipment to help you.
- Spirituality such as your faith or beliefs and whether your cancer experience has affected these.

For some practical or financial issues, your healthcare worker may refer you to other health or social care services. These will give you further advice and support.

Remember the concerns we have listed above are only a guide. Not everything listed will apply to you. Or you may have concerns that are not listed. We have some suggestions to help you decide what you would like to discuss (see page12).

Preparing for your discussion

You may find it helpful to make notes of any concerns or questions you have before the discussion.

You may want to think about these questions:

- Are you coping ok?
- Is cancer affecting your relationships with family or friends?
- Are family and friends coping with your diagnosis?
- Would you like to know more 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 to be 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 out for and who to contact if you notice any?
- Do you know who to contact if you have any problems?
 For example, do you have the contact details of your key worker?

Not all these suggestions will be relevant to you. The HNA is about your personal needs and concerns.



Your care plan

During the discussion, you and your key worker will agree on the best ways to manage your needs and concerns. They may write down what you have agreed in a document called a care plan. This is sometimes called a personalised care and support plan. They may write it during the discussion. Or they may make notes and send it to you afterwards.

Your care plan will record:

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

Your key worker usually gives you a copy of your care plan. If your discussion is with a cancer support worker, your final care plan will always be agreed with your key worker. If you are not offered a copy of your care plan, you can ask your key worker for one 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 for example, a dietitian or counsellor.

Your key worker will only share your care plan with your permission. They will only share as much information as people need to help with your care.

Your care plan will be securely stored 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

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/ information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- · easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats** If you would like us to produce information in a different format for you, email us at **cancerinformationteam@ macmillan.org.uk** or call us on **0808 808 00 00**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/ informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org. uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to meet other people going through the same things. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

Help with money worries

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support.

General cancer support organisations

Maggie's Centres

Tel 0300 123 1801 Email enquiries@maggiescentres.org www.maggiescentres.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 9am to 5pm) Email **bacp@bacp.co.uk www.bacp.co.uk** Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

Financial support or legal advice and information

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline 03444 111 444 www.citizensadvice.org.uk

Wales Helpline 03444 77 2020 www.citizensadvice.org.uk/wales

Scotland Helpline 0808 800 9060 www.cas.org.uk

Northern Ireland

Helpline 0800 028 1881 www.citizensadvice.co.uk

General health information

Health and Social Care in Northern Ireland

online.hscni.net Provides information about health and social care services in Northern Ireland.

NHS.UK

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** (Mon to Fri, 8am to 10pm, Sat and Sun, 9am to 5pm) **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.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000 Email enquiries@phe.gov.uk www.ncras.nhs.uk Tel (Ireland) 021 4318 014 www.ncri.ie

Scottish Cancer Registry

Tel 0131 275 7050 Email nss.csd@nhs.net www.isdscotland.org/health-topics/cancer/ scottishcancer-registry

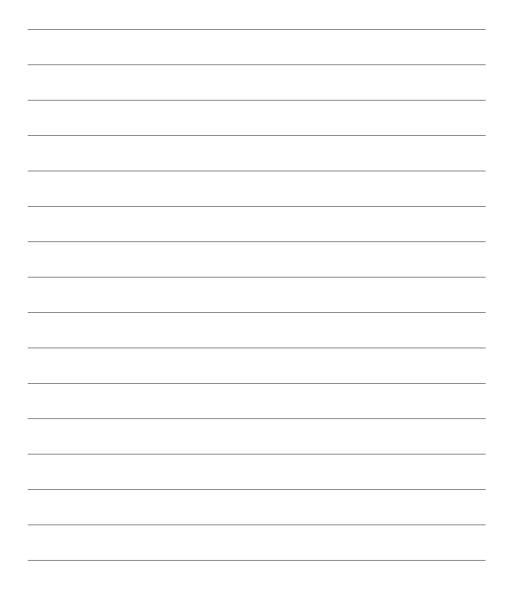
Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500 Email general.enquiries@wales.nhs.uk www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028 Email nicr@qub.ac.uk www.qub.ac.uk/nicr

Your notes and questions



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 booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Prof Tim Iveson, Macmillan Chief Medical Editor.

With thanks to: Professor Deborah Fenlon, Professor of Nursing; Dr Pauline Love, Macmillan GP; Avril Van der Loo, Macmillan Recovery Package Programme Manager; and Jane Wraight, Clinical Nurse Specialist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact cancerinformationteam@macmillan.org.uk

Sources

We have listed a sample of the sources used in the leaflet below. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

European Society for Medical Oncology: Supporting self-management of patients and family members. 2019.

Johnstone et al. The implementation and impact of Holistic Needs Assessments for people affected by cancer: a systematic review and thematic synthesis of the literature. European Journal of Cancer Care. 2019. Vol 28.

Macmillan Cancer Support. Providing personalised care for people living with cancer: a guide for professionals providing holistic needs assessments, care and support planning. 2019.

Maher, J et al. Implementation of nationwide cancer survivorship plans: Experience from the UK. Journal of Cancer Policy. 2018. Vol 15, pp 76-81.

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money

Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £ (Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

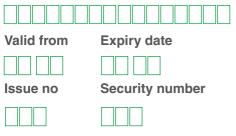
□ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

Card number



/

If you would rather donate online go to macmillan.org.uk/donate



Signature

Date /

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This leaflet is about a Holistic Needs Assessment (HNA). An HNA identifies any concerns you may have when you are diagnosed with cancer. These may be physical, emotional, practical, financial and spiritual.

The leaflet talks about what happens at an HNA and has information about making a care plan.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am 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.

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