

**HOLISTIC NEEDS
ASSESSMENT**

**CARE AND
SUPPORT
PLANNING**

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About this guide

Every person's experience of living with a cancer diagnosis will be different. A Holistic Needs Assessment (HNA) can help you tailor the care and support you provide to meet their needs. In using a structured process for HNAs you will be able to identify and record the many different needs or concerns that may arise. Over the next few pages, we'll explain how the HNA process works.

Note: When we refer to 'HNA', we mean the Holistic Needs Assessment, as well as care and support planning consultations.



Contents

Background and introduction	3
Why is an HNA important?	4
Common misconceptions about HNAs	5
Benefits of HNAs	7
Eight key principles of an HNA	9
Implementing HNA care and support plans within a clinic	11
Tips on HNA care and support planning delivery	13
Training and skills required for HNAs	17
Dealing with emotions	19
Assessment tools	21
Acknowledgements and references	22

Background and introduction

We know that there are currently 2.5 million people living with and beyond cancer in the UK today and that this figure is likely to double to 4 million by 2030. With so many people living with cancer, it's important to make sure the care provided can be adapted to different needs. The Holistic Needs Assessment (HNA) care and support plan helps to do just that.

HNA care and support planning is not a new skill. In fact it has been developed using more than 10 years of research and evidence from a number of worldwide cancer providers.

Supported by UK policy

The following are the latest policy documents for England and Scotland that are promoting the use of Holistic Needs Assessments. Health organisations in Northern Ireland and Wales are planning similar strategies.

England:

In October 2014, the NHS published its Five Year Forward View¹. This recommended using HNA care and support planning as part of the Recovery Package for a person living with cancer.

In May 2015 the Achieving World Class Cancer Outcomes – A strategy for England 2015–2020² was published. Recommendation 49 says 'Pilots, through new or existing vanguard sites, assessment of holistic needs for cancer

patients at the point of diagnosis, evaluating the benefit of earlier palliative care and/or intervention from Allied Health Professionals (AHP).

Scotland:

The Scottish Cancer Strategy, Beating Cancer: Ambition and Action 2016³ is a report that looks closely at the Transforming Care after Treatment Programme. It focuses on making follow-up care personal to everyone, using an HNA and individual care plan.

Why is an HNA important?

There is mounting evidence that shows the more concerns people with cancer have the more distressed they feel. But it can be difficult for people to discuss what's worrying them, or for healthcare professionals to pick these concerns up.⁴

This may be because lots of cancer patients are reluctant to be seen as 'complaining'.⁴

A structured HNA can help to identify a person's concerns and needs so that together you can try to address them and provide support when needed.

Aims of an HNA

- To provide a holistic (i.e. bio-psycho-social-spiritual) assessment of patients' concerns following a diagnosis of cancer, through treatment and beyond.
- To provide the healthcare professional with insight into patients' coping skills. This enables you to signpost patients to services that will support them to address their concerns.
- To identify methods or strategies of self-care that the patient may be able to adopt to help resolve or manage their concerns.

Aims of Care & Support Planning

- To document the patient's concerns identified within the HNA.
- To summarise the required actions of both the professional and patient.
- To resolve or reduce anxiety levels for the concerns raised.

Common misconceptions about HNAs

You might think that an HNA is like opening a can of worms: that a person's concerns aren't relevant to cancer so you won't be able to answer or deal with them. In this section, we discuss some of the misconceptions that we often hear about HNAs.

Things you might think	What we've found
<i>'I don't need to do an HNA because I already know which patients need help.'</i>	In other areas where very experienced healthcare professionals have started to use HNAs, they were surprised at the issues they discovered. Some patients who seemed to be coping well on the outside had really serious concerns that they hadn't talked about.
<i>'Not everyone with cancer needs an HNA – it's only for people who need palliative care.'</i>	You don't know this for sure if you don't ask. All people with cancer should be offered the opportunity of an HNA at least once. Not everyone will want the full assessment conversation.
<i>'Every HNA takes ages and I don't have the time.'</i>	HNAs might not take as long as you think. Evaluation of Ipsos Mori eHNA ⁵ showed that on average assessments took 7 minutes. Using a tool such as the distress thermometer, Concerns Checklist or SPARC helps to structure the conversation. This means you can quickly focus on the most important issues for patients.

'I don't like the tool we're meant to use. It feels like more paperwork and box-ticking.'

Don't let the tool dictate the whole HNA process. The tool is only there to help you cover everything you need to in your assessments and make a record of that. An HNA definitely shouldn't be a box-ticking exercise for patients. It should be an important part of the care they receive.

'I already do HNAs but I don't follow the exact tools and guidance from my network.'

That's great. But make sure you:

- Cover all concerns and not just the ones you are comfortable with.
- Don't make assumptions that a question isn't relevant for that patient – if you don't ask you won't know.
- Record the outcomes in the patient's action or care plan in the same way.

Benefits of HNAs

For the health and social care professional

An HNA will help to focus the conversation on the things that are most important to the patient, which can make the job more rewarding. It can also support the aims of providing care that's more focused on individual needs and helping people to support themselves.

Secondly, particularly when you're using the electronic tool, an HNA can show the full scope of the work covered with the patients every day. This can be used in job plans to illustrate staff roles and contribution to patient care.

The electronic tool also provides real-time data about people's needs and concerns. As this data builds up, you can start to look for overall patterns, as well as providing evidence of service areas you might be able to improve (eg. benefits advice, dietetics or pain control).

Finally, when used in the context of the cancer multidisciplinary team (MDT) discussion, it can inform the wider cancer team about the holistic needs of the patient. This ensures that the care and support needs of the individual are taken into account within those discussions. This is part of the Cancer Peer Review Measures requirement.⁶

For your patients

The HNA can make a big difference to the overall patients' experience of their care. It can help them realise that their concerns are important and not unusual. It opens the door for discussion and it can help inform people about further support. It may encourage people to seek help straight away, preventing a concern becoming more acute.

Evidence has shown that the most helpful part of the HNA process is the discussion between the HCP and the patient.⁵ Using an HNA tool provides a quick and easy way for the person affected by cancer to highlight their concerns. This can help them to feel more understood, no matter what they are going through.




An HNA might not resolve every problem or concern that a person mentions. But the conversation itself can often be a therapeutic experience for people living with cancer. It can also help you to decide whether people need support from specialist teams or agencies.

The care or support plan should include what the patient can do too. This should be supported by up-to-date information on local resources like healthy lifestyle projects, benefits advisors, support groups and programmes to encourage independence.








Marina, Macmillan Lung Cancer Clinical Nurse Specialist, and Sylvia

Eight key principles of HNAs

-  **An HNA is a normal, routine assessment and part of the care pathway.**
-  **Preparation is key to success** – the patient should know what to expect and why they are attending. It's a chance to work together and focus on the person, not just their cancer.
-  **Build rapport and trust** before expecting the patient to talk about anything very personal. Take your time and talk generally about how things are going before you ask any HNA questions. For example, 'How have you been coping with the treatment so far?'



Shelagh, Macmillan Partnership Quality Lead, and Robert

-  **Be specific.** For example, 'You've said you get insomnia; can you tell me a bit more about that? What's your sleep pattern normally like? Okay, so what do you think is happening when you find yourself awake at night?'
-  **Highlight the patient's own coping skills.** Reassure the patient that they're not powerless and they can manage some of their own problems. For example you could ask, 'What do you think might help to improve your sleeping?' Acknowledge **their self management skills** and build on things that go well.
-  **Focus your HNA on solutions** rather than getting stuck on the problem itself. For example, 'Shall we move on to what we could do about this problem?' 'Can you think of one thing that might improve your situation even slightly?'
-  **It's a chance to talk.** Assessing someone isn't a form of therapy in itself. But it's often therapeutic for people to talk about their experiences and understand that their feelings are normal. So keep your HNA sessions talkative and don't let people think that their concerns are unusual or a big part of their medical condition.
-  **Signpost people for further support** to other resources or organisations that you think might offer valuable help.



Keynes, Dietician

Implementing HNA care and support plans within a clinic

Although HNA is a normal part of the care pathway it's advisable that teams understand their capacity to provide them. To do this we recommend that teams should do some strategic planning to help them achieve success.

Map the pathway: This will help determine at what stage of the pathway the HNAs are best provided.

Although there's no right or wrong time to assess a person's needs and concerns, there are some times when it's just not appropriate. It's not advisable to give an HNA when providing significant news about a diagnosis or progression.

Mapping the patient pathway will help you identify :

1. Who's eligible for an HNA. Consider local CQUIN measures or tariffs.
2. Which team member is best suited to carry out an HNA. Who has the skills and who needs training?
3. Whether you know which local resources can support people and provide the information they need. If not, consider creating a local directory of services.
4. Which stage on the pathway is the best time to carry out an HNA. For instance, if the pathway involves passing care to a team in another organisation, work out which team is best suited to doing the HNA.
5. Whether an HNA fits into the Clinical Nurse Specialist (CNS) job plan. Think about whether you have protected time to do HNAs, and whether your clinic times are suitable for doing them. For example, would evening/ telephone clinics be better?
6. Where the best location is. You'll need a place that's safe and private to do the assessment and care and support planning. Your patients need to feel as comfortable as possible talking about their concerns.

Have a look at our at our short animations at macmillan.org.uk/HNA. The animations show why it's important to do HNAs and how HNAs can be implemented in your healthcare setting.

Tips on HNA care and support planning delivery

HNAs take an average of seven minutes to complete. The HNA questionnaire is something your patients should complete on paper or on a tablet.

It's important that the clinic is prepared. Here are some other things you should consider:

- Think about additional support that maybe needed for such as: language, vision and literacy (never assume everyone can read).
- Provide the patient with information before the assessment so that they know what to expect. Macmillan has a booklet to help people prepare for HNAs; it's available at macmillan.org.uk/havinganhna
- Word the clinic invite letter clearly. You should explain how long the appointment will take and, if possible, who it will be with.
- Provide space where the patient can complete their HNA questionnaire.
- Ensure there are tissues in the room, just in case.
- Set a time frame for the appointment.
- Consider writing a short script that helps staff introduce the HNA.



Here are examples of HNA introduction scripts:

'Hi, my name is... Your appointment today is about you, your concerns and looking at how we can support you. So that we can do that, would you mind doing a short assessment? It's a quick and simple way for you to tell us any concerns you might have had over the last week. It'll help us provide the information and support you may need.'

'So I'd like to spend some time with you now to look at how you've been managing. It's an opportunity for you to tell me about anything that concerns you. And maybe we can think together about the best ways that we can deal with those concerns.'

If the patient says 'No' at this point, reassure them that's fine and they're welcome to have an informal discussion. Feel free to ask why people don't want to do HNAs as long as you ask gently and respectfully.

Providing support

Some patients will really open up as part of their HNA and that might be upsetting. It's important you know that you didn't cause the distress by asking about it. Patients will often find it very helpful knowing that someone has taken the trouble to listen to their feelings. So it's essential to find a quiet,

private setting and ensure that you have tissues available in case they're needed. Clinical supervision for staff undertaking HNAs should be made available.

It's vital to balance the need for privacy with staff safety, and to remember that there are limits to patient confidentiality. For example, if there's a risk of

a patient harming themselves or others, what protocols are in place for this eventuality?

An HNA should focus on an individual and a one-to-one setting is usually best. However there are some exceptions:

- Someone with special needs might need a family member or care worker to be with them. For example, someone with a learning disability might need a carer to help with communication. A deaf person might need a sign language interpreter.
- Someone whose first language isn't English might need an interpreter.
- Some people might insist that they need the support of a friend or relative.

Whether your assessment is one-to-one or not, every patient should be encouraged to talk freely and explain their own concerns.

The purpose of the care plan is to support the patient. Concerns should be described using the same language the patient would use and avoid medical jargon.

Picking the right place

Healthcare settings are usually hectic, noisy and lack privacy. The HNA covers some very personal information so it's really important to do it in a quiet private space. It's also important that the person carrying out the HNA can't be disturbed or called away.

If you're using the electronic HNA (eHNA) tool there are some other things you will need to think about:

- Is there a tablet or similar device available at the time of the appointment?
- Can you connect to the WiFi?
- Is there a desktop or laptop to write up the care and support plan? Will this be written at the time of the care planning consultation or afterwards? Is there a printer within easy reach?



Shez, Macmillan Neuro Oncology
Clinical Nurse Specialist

Training and skills required for HNAs

For experienced health and social care professionals assessing patients needs is not a new skill. An HNA simply provides a structure to show that the assessment and care plan have taken place.

Four levels of practice in the provision of psychological support for cancer patients were outlined in Improving Supportive and Palliative Care for Adults with Cancer.⁷

Non-clinical staff providing HNAs, who might be working at level 1 can give general emotional support. Level 2 staff providing HNAs can offer support for psychological distress. They should also have clinical supervision from staff working at level 3 or 4.⁷

A Competency Framework for Nurses – Caring for Patients Living with and beyond Cancer was developed in 2014.⁸ The framework provides more information on the skills and competencies you need when you're caring for patients with a cancer diagnosis. It can help you identify ways to improve your skills. This can be adapted for non-clinical staff such as support workers.

You might want to think about going on a course such as:

- **Advanced communication**

This covers: handling difficult questions; working with strong emotions like anger, anxiety and depression; managing denial/collusion; and working with colleagues.

- **SAGE and THYME**

sageandthymetraining.org.uk

- **Mindfulness.**

- **Screening for psychological distress.**

- **Motivational Interviewing.**

At a glance, the core skills you'll need are as follows.

Communication:

- communicate and empathise with people from a wide range of backgrounds.
- show respect for people and be willing to listen to their concerns.
- demonstrate openness through good eye contact, voice control, pace and seating positions.
- listen to and hear concerns and know how to respond to them.
- allow people to explore their own support and their own solutions.
- help people to prioritise concerns and solutions when they have several.

Problem-solving:

- ask people to describe problems and concerns in detail.
- talk through possible options but don't feel limited to only 'sensible' or obvious ones.
- describe pros and cons of each option by picturing what might happen.
- help people to decide on the best solution for them personally.
- make it clear which steps they need to take to reach this solution.
- agree to work towards the solution, if possible within an agreed period of time.

Dealing with emotions

An HNA sometimes makes people feel all sorts of emotions that they've been keeping to themselves. It's important to remember that these emotions were there before your interview began – don't feel responsible for them. In fact emotional expression can be really therapeutic so crying can be a good way to release pent-up feelings. Don't be tempted to try and 'fix' a problem straight away; let your patient express themselves and explore everything in plenty of detail. Then think about how you can help people to solve their own problems.

This approach means you're working together with your patient and you're not just a professional telling someone what to do. At the end of the assessment, particularly if it's been an emotional one, encourage a person to take stock of the past few minutes. Ask them what they're going to do with the rest of their day. This helps to bring them back to the present and give a feeling of closure to an interview.

Suicidal feelings and risk assessment

Some people living with cancer will think about committing suicide. It might seem like a way to regain control or escape from suffering. In fact it's fairly common for people to think these thoughts. But if someone is really thinking hard about ways to commit suicide then they might have lost hope, become very depressed or be a genuine risk to their own safety.

Under these circumstances, it's understandable for a healthcare professional to feel anxious about confronting the issues at hand. But please remember that talking about things won't make anyone commit suicide. If anything it might make them feel a bit better. So don't avoid the topic – lots of the things that make people want to kill themselves are preventable or can be relieved. Talk to someone about all the things that make them think about suicide. This way you can understand why they feel a particular way, and how long it's been going on for. You can also work out whether you need to refer the person to other specialists.

For example, some people might feel suicidal because they're in a lot of pain. In which case perhaps they haven't been given the right treatment for that symptom. You could treat this with analgesia or explain how palliative care might help in the future. If someone is struggling to cope with a sense of loss, you might be able to put more support in place to help them adapt to life changes. Perhaps a person living with cancer feels like their life is out of control. If so, maybe you could work together to find areas where the person could regain control, feel more valued or carry out satisfying tasks.

No matter what, if a person seems depressed, you shouldn't be afraid to refer them to a specialist.

If a patient does describe suicidal thoughts or intentions to you, tell them that you'll let their GP know straight away. That should be in addition to any other action you take. This is an occasion where you're allowed to break patient confidentiality but you do need to be open and honest with the patient about this (NMC Code of Professional Conduct 2015 [point 5.4]).

It's also really important that you know and understand a patient's condition and their full treatment and care history when providing the HNA.



Judith, Macmillan Nurse Consultant in Cancer and Palliative Care, and Andrew

Assessment tools

The use of an assessment tool to provide HNAs can ensure a consistent approach within a clinical team or hospital. There are several different HNA tools that can support HNA, and teams should decide on which tool suits their needs most. Each tool generally covers six main areas of need:

- Practical,
- Physical,
- Emotional,
- Spiritual,
- Mental,
- Social.

Macmillan has developed the Concerns Checklist, which is available on paper (triplicate) format and electronically. If you are interested in using either of these, please go to be.macmillan.org.uk and search for MAC13689. Visit signup.mycareplan.co.uk for the sign-up tool. Alternatively, please contact eHNA@macmillan.org.uk

National Cancer Survivorship Initiative – Concerns checklist Holistic needs assessment

Identifying your concerns

Discussed by: _____
 Date: _____
 Designation: _____
 Contact details: _____

Patient's name or label

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

I have questions about my diagnosis/treatment that I would like to discuss.

<p>Physical concerns</p> <ul style="list-style-type: none"> <input type="checkbox"/> Breathing difficulties <input type="checkbox"/> Passing urine <input type="checkbox"/> Constipation <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Eating or appetite <input type="checkbox"/> Indigestion <input type="checkbox"/> Sore or dry mouth <input type="checkbox"/> Nausea or vomiting <input type="checkbox"/> Sleep problems/nightmares <input type="checkbox"/> Tired/exhausted or fatigued <input type="checkbox"/> Swollen tummy or limb <input type="checkbox"/> High temperature or fever <input type="checkbox"/> Getting around (walking) <input type="checkbox"/> Tingling in hands/feet <input type="checkbox"/> Pain <input type="checkbox"/> Hot flushes/sweating <input type="checkbox"/> Dry, itchy or sore skin <input type="checkbox"/> Wound care after surgery <input type="checkbox"/> Changes in weight <input type="checkbox"/> Memory or concentration <input type="checkbox"/> Taste/sight/hearing <input type="checkbox"/> Speech problems <input type="checkbox"/> My appearance <input type="checkbox"/> Sex/intimacy/fertility 	<p>Practical concerns</p> <ul style="list-style-type: none"> <input type="checkbox"/> Caring responsibilities <input type="checkbox"/> Work and education <input type="checkbox"/> Money or housing <input type="checkbox"/> Insurance and travel <input type="checkbox"/> Transport or parking <input type="checkbox"/> Contact/communication with NHS staff <input type="checkbox"/> Laundry/housework <input type="checkbox"/> Washing and dressing <input type="checkbox"/> Preparing meals/drinks <input type="checkbox"/> Grocery shopping <p>Family/relationship concerns</p> <ul style="list-style-type: none"> <input type="checkbox"/> Partner <input type="checkbox"/> Children <input type="checkbox"/> Other relatives/friends <p>Emotional concerns</p> <ul style="list-style-type: none"> <input type="checkbox"/> Difficulty making plans <input type="checkbox"/> Loss of interest/activities <input type="checkbox"/> Unable to express feelings <input type="checkbox"/> Anger or frustration <input type="checkbox"/> Guilt <input type="checkbox"/> Hopelessness <input type="checkbox"/> Loneliness or isolation <input type="checkbox"/> Sadness or depression <input type="checkbox"/> Worry, fear or anxiety 	<p>Spiritual or religious concerns</p> <ul style="list-style-type: none"> <input type="checkbox"/> Loss of faith or other spiritual concerns <input type="checkbox"/> Loss of meaning or purpose of life <input type="checkbox"/> Not being at peace with or feeling regret about the past <p>Lifestyle or information needs</p> <ul style="list-style-type: none"> <input type="checkbox"/> Support groups <input type="checkbox"/> Complementary therapies <input type="checkbox"/> Diet and nutrition <input type="checkbox"/> Exercise and activity <input type="checkbox"/> Smoking <input type="checkbox"/> Alcohol or drugs <input type="checkbox"/> Sun protection <input type="checkbox"/> Hobbies <input type="checkbox"/> Staying in returning to work and education <input type="checkbox"/> Making a will <input type="checkbox"/> Other
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Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.

1

10

Lowest Highest

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Other tools are:

- **Sheffield Profile for Assessment and Referral for Care (SPARC)** – ncbi.nlm.nih.gov/pubmed/23414548⁹
- **Hospital Anxiety and Depression Score (HADS)** sciencedirect.com/science/article/pii/S016383439390099A¹⁰
- **Social Difficulties Inventory (SDI)** onlinelibrary.wiley.com/doi/10.1002/pon.1705/abstract¹¹
- **Patient Concerns Inventory (PCI)** patient-concerns-inventory.co.uk

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