

PROVIDING PERSONALISED CARE FOR PEOPLE LIVING WITH CANCER

A guide for professionals providing
holistic needs assessments, care
and support planning

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CANCER SUPPORT
RIGHT THERE WITH YOU

Personalised care

Personalised care means people have choice and control over the way their care is planned and delivered. It's based on what matters to them and their individual strengths and needs.

Making care personalised aims to support people with cancer make decisions about their care through identification of their concerns and goal setting facilitated by professionals/AHPs/Key workers.

People living with cancer also live with other long-term conditions which may impact on their holistic needs once they get a cancer diagnosis. A personalised approach to care and support planning, using a Holistic Needs Assessment (HNA), ensures people's needs can be fully identified and appropriate support planned.

That's why Macmillan Cancer Support is advocating for people living with cancer to receive an HNA and a Personalised Care and Support Plan (PCSP). It's their individual guide through their cancer journey, from diagnosis onwards.

Macmillan's proposition for how personalised cancer care should be delivered in local services consist of 5 core components:

1. Everyone diagnosed with cancer has a **supportive conversation**
2. Health and wellbeing information resources are made available during the conversation and throughout a person's cancer journey
3. The person's needs are **assessed in line with an HNA approach**
4. A **personalised care and support plan**, facilitated by the assessment, is developed with the person living with cancer
5. Every person with cancer can access help by **navigating the care and support they need**, including health and wellbeing support, community services and digital tools and resources

Macmillan warmly welcomes the commitment to Personalised Care and the NHS Long-Term Plan¹ that *“every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan, health and wellbeing information and support, all delivered in line with the Comprehensive Model for Personalised Care”*².

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Sharon, Macmillan Secondary Breast Cancer Clinical Nurse Specialist

Background and introduction

The number of people living with cancer is set to rise to 5.3 million by 2040. We know that 70% of people with cancer have other long-term conditions to manage alongside cancer. Changes in treatment options and delivery models mean people may have continuing treatment for longer periods and more complex side effects, along with newer treatments such as immunotherapy delivered in a community setting. Macmillan is clear that this requires cancer care and support to be delivered across boundaries, with health and care providers collaborating closely together to provide personalised care across the cancer pathway.

New policy initiatives set an exciting, ambitious agenda for personalised care. The NHS Long Term Plan¹ highlights cancer as a major priority for the health and care system over the next 10 years.

Personalised care means people have choice and control over the way their care is planned and delivered. It is based on what matters to them and their individual strengths and needs. Personalised care is fundamental to delivering better quality, integrated care that is meaningful to the individual, supporting improvements in health and wellbeing.

By 2021, where appropriate, every person diagnosed with cancer will have access to personalised care, including an assessment of their needs, a care plan, and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care.² This will empower people to manage their care and the impact of their cancer and help them receive digital and community-based support, ensuring they will have access to the right help and expertise.

Supported by UK policy

The following are the latest policy documents for the UK promoting the use of Holistic Needs Assessments.

Wales

Welsh Government published 'A Healthier Wales' in 2018, this provides a long term vision for the future of health and social care in Wales. It outlines how Wales will move towards a more integrated system of care through the use of technology and workforce development.

In Wales, the Cancer Delivery Plan provides direction for the future of cancer services.

The document published in 2016 places a firm emphasis on person centred care and early diagnosis. The Plan will conclude in 2021, with a future strategy expected for cancer services and in line with 'A Healthier Wales'.

In 2018, the new First Minister of Wales, Mark Drakeford AM, committed to enabling every person affected by cancer to have access to an assessment of their wider holistic needs. This is currently in development, but expected to be met by 2021.⁶

Scotland

The Scottish Cancer Strategy, *Beating Cancer: Ambition and Action 2016* is a report that looks closely at the Transforming Care after Treatment Programme.⁵ It focuses on personalising follow-up care and using an HNA.

England

In January 2019 NHS England published its Long-Term Plan.¹ This ambitious 10-year plan sets out a new approach to improve both the quality of care and health outcomes. It has a focus on personalised care to ensure everyone living with cancer gets the right support to meet their needs, building on the 2015 Cancer Strategy commitments.

Shortly afterwards NHSE published Universal Personalised Care, its delivery plan for implementing the Comprehensive Model of Personalised Care. This model sets out a series of six components of personalised care, including supported self-management, personalised care and support planning and social prescribing. Also in January 2019, the new GP contract for England was published, introducing a number of elements that support the rollout of personalised care, including national service specifications for personalised care, early cancer diagnosis and anticipatory care for high need patients, such as those with multiple long term conditions. These will be delivered by new primary care networks, bringing together GP practices. These networks consist of multi-disciplinary teams of primary and community care professionals, including new link worker roles which will enable the roll-out of social prescribing.

Northern Ireland

The Bengoa report, *Systems, Not Structures: Changing Health and Social Care* (2016) published by the NI Department of Health was followed by *Health and Wellbeing 2026: Delivering Together* (2017), a ten-year approach to transforming health and social care. Plans to develop a cancer strategy for NI have been implemented by the Department of Health with the strategy due for completion in 2020⁷

How HNAs facilitate effective Personalised Care and Support

There is mounting evidence that shows that the greater number of concerns people living with cancer have, the more distressed they feel. This can lead to increased anxiety and isolation, and impacts their ability to undertake usual daily tasks, work, and can affect their relationships.

People may find it difficult to discuss what is worrying them, and an HNA is a structured way for the person to identify their concerns and receive support. Once their concerns are identified and discussed, a personalised care and support plan can then be developed. This may be with suitable professionals such as clinical nurse specialists, allied healthcare professionals or support workers, depending on the needs and concerns raised.

Aims of an HNA:

- To provide a broad (biological-psychological-social-spiritual) assessment of an individual's concerns following a diagnosis of cancer, through treatment and beyond
- To provide health and care professionals with insight into a person's coping skills, enabling effective signposting to local services to support their needs
- Identify self-care methods or strategies that a person may utilise when resolving or managing their concerns

Aims of personalised care and support planning:

- To have a supportive conversation
- Understand what is important to the individual and who can help
- Identify what support they may need to self-manage
- To resolve or reduce anxiety levels for the concerns raised
- Helping to document and prioritise concerns identified by the HNA and enable a structured approach for the action plan
- The overarching aim of personalised care and support planning is to support people who live with cancer and to develop their knowledge, skills and confidence to manage their own health, care and wellbeing.

Benefits of personalised HNAs

For health and social care professionals

An HNA will help focus conversations you have with people affected by cancer and hone in on things that matter to them. It can also support the aims of providing care that's more focused on personal needs and helping people to support themselves.

Particularly when you're using the electronic version (eHNA), it can enable identification of interventions in a more systematic way.

This can be used in job plans to illustrate staff roles and their contribution to care.

The eHNA 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 (e.g. benefits advice, psychological support, pain control, etc).

Finally, when used in the context of the cancer multidisciplinary team (MDT) discussion, it can inform the wider cancer team about the concerns of the people living with cancer.

This ensures that the care and support needs are taken into account within those discussions. This is part of the Cancer Peer Review Measure requirement.⁸

For people living with cancer

The HNA can have significant impact to people's overall cancer experience and their care. It can help them realise that their concerns are important and can be addressed. It opens the door for discussion and it can help inform people about further support.

Undertaking a HNA and a personalised care and support plan can identify concerns not previously raised. It can also reduce the likelihood of concerns becoming more problematic at a later stage.

Evidence has shown that the most helpful part of the HNA process is the discussion between the HCP and the individual.^{9,10}

Using an HNA provides a structured way for the person living with cancer to highlight their concerns. This can help them to feel more understood, no matter what they are going through. Personalised approaches enable people to identify their own needs and make choices about how and when they are supported to live their lives. Providing a HNA means people can have access to information, advocacy and advice so they can make informed decisions.

Supportive Conversations

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 identify whether they need support from specialist teams or agencies. A record of the conversation should then be captured in the care or support plan and should include what the person can do for themselves. This can be supported by up-to-date information on local resources like healthy lifestyle, benefits advisory services, support groups and programmes to encourage independence.



Marina, Macmillan Lung Cancer
Clinical Nurse Specialist,
and Sylvia

Eight key principles of HNAs to support personalised care

An HNA is a normal and routine assessment which can be used as part of the care pathway to help support people with cancer. There are eight key principles which are:



Preparation is key to success. The person should know what to expect and why they are attending. It's a chance to work together and not to focus just on their cancer.



Build rapport and trust before expecting someone to open up and talk about anything very personal. Take your time and talk generally about how things are going before you ask any HNA questions. For example, you could ask 'How have you been coping with the treatment so far?'



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 coping skills. Reassure those being assessed 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. HNA sessions should be person centred and, where possible, normalise concerns.



Signpost people for further support to other resources or organisations that you think might offer valuable help.

Implementing HNA

care and support planning

Although care planning is a normal part of the care pathway, it's advisable that teams understand how they can optimise the process.

Mapping the journey will help determine delivery opportunities and ensure consideration is given to engaging those undertaking the HNA.

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

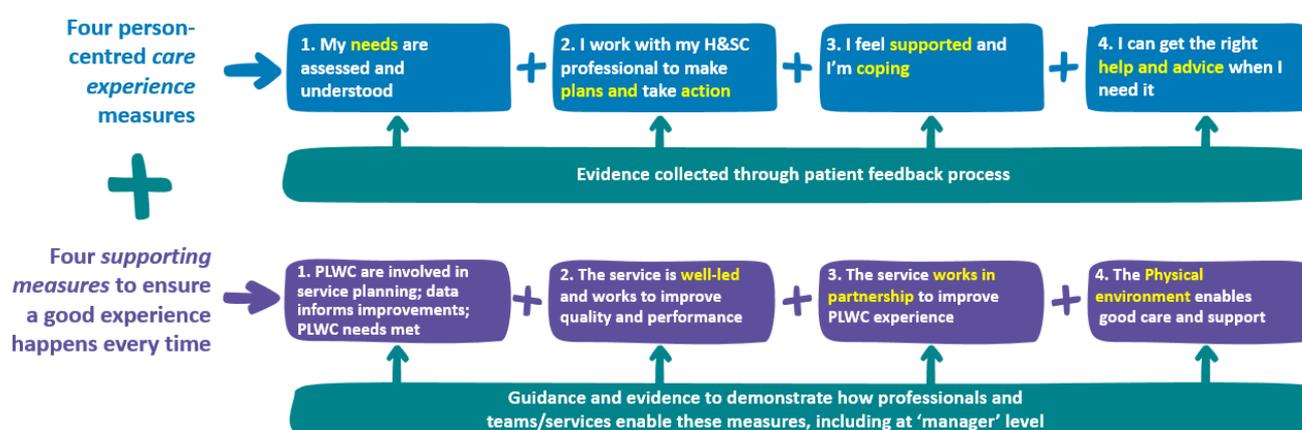
Mapping the care pathway will help you identify:

1. The setting that the HNA is offered in should be considered safe and private
2. Who is eligible for an assessment? And who will be excluded and why?
3. 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
4. Whether you have adequate time to do HNAs and how they may be delivered
5. Who has the skills and who may need training? What training will they need?
6. Whether you know of local resources to support people and provide the information they need. If not, consider creating a local directory of services
7. Consider local CQUIN measures or tariffs and how data will be collected and reported.

Measuring successful delivery

It's important to regularly evaluate your HNA service to ensure it is meeting the needs and outcomes expected. Most organisations providing HNAs are tasked with reporting on the numbers of Personalised Care and Support Planning provided. This data gives a good quantitative view of delivery. However, when it comes to quality of service things often get a little tricky. Gathering user feedback is one key way to ensure that your service is meeting the needs of its users.

Quality Together is the Macmillan quality standard, designed to help teams to describe what a good, high-quality person-centred experience looks like. The standard is centred around four experience measures, evidenced primarily through patient feedback and associated action plans, and an additional four key principles to support effective service planning and delivery. By providing measures to describe what 'good' looks like, guidance and examples of the evidence needed as well as links to tools and resources, *Quality Together* supports professionals to ensure a positive patient experience.



Quality Together is an integral part of the Macmillan Quality Improvement Framework which is built around relationships, identified as quality conversations that are relational rather than process driven.

1. We engage stakeholders in improving our services
2. We understand and monitor our operational performance
3. We attain and maintain our service quality standards
4. We develop and implement effective and timely action plans
5. We exercise improvement leadership at all levels
6. We create and sustain a culture of continuous learning

Further information is available by contacting qualityimprovement@macmillan.org.uk

Assessment tools available

The use of an assessment tool to provide HNAs can ensure a consistent approach within a team or organisation. 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

Concerns Checklist - identifying your concerns

Patient's name or label

Key worker: _____

Date: _____

Contact number: _____

This self assessment is optional. It has been designed to help us support you by identifying any concerns you may have and information you may require.

What do I need to do?
Select any areas that may have caused you concern recently and you would like to discuss with your key worker. When selecting please score each concern between 1-10, with 1 being low level of concern and 10 the highest.

Key worker to complete Copy given to patient
 Copy to be sent to GP

I have questions about my diagnosis, treatments or effects

Physical concerns

- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating, appetite or taste
- Indigestion
- Swallowing
- Cough
- Sore or dry mouth or ulcers
- Nausea or vomiting
- Tired, exhausted or fatigued
- Swelling
- High temperature or fever
- Moving around (walking)
- Tingling in hands or feet
- Pain or discomfort
- Hot flushes or sweating
- Dry, itchy or sore skin
- Changes in weight
- Wound care
- Memory or concentration
- Sight or hearing
- Speech or voice problems
- My appearance
- Sleep problems
- Sex, intimacy or fertility
- Other medical conditions

Practical concerns

- Taking care of others
- Work or education
- Money or finance
- Travel
- Housing
- Transport or parking
- Talking or being understood
- Laundry or housework
- Grocery shopping
- Washing and dressing
- Preparing meals or drinks
- Pets
- Difficulty making plans
- Smoking cessation
- Problems with alcohol or drugs
- My medication

Emotional concerns

- Uncertainty
- Loss of interest in activities
- Unable to express feelings
- Thinking about the future
- Regret about the past
- Anger or frustration
- Loneliness or isolation
- Sadness or depression
- Hopelessness
- Guilt
- Worry, fear or anxiety
- Independence

Family or relationship concerns

- Partner
- Children
- Other relatives or friends
- Person who looks after me
- Person who I look after

Spiritual concerns

- Faith or spirituality
- Meaning or purpose of life
- Feeling at odds with my culture, beliefs or values

Information or support

- Exercise and activity
- Diet and nutrition
- Complementary therapies
- Planning for my future priorities
- Making a will or legal advice
- Health and wellbeing
- Patient or carer's support group
- Managing my symptoms
- Sun protection

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Macmillan has developed the Concerns Checklist, which is available on paper (triplicate) format, or electronically in additional languages. For more information 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

Other HNA tools are:

- **Sheffield Profile for Assessment and Referral for Care (SPARC)**
ncbi.nlm.nih.gov/pubmed/23414548¹²
- **Hospital Anxiety and Depression Score (HADS)**
sciencedirect.com/science/article/pii/S016383439390099A¹³
- **Social Difficulties Inventory (SDI)**
onlinelibrary.wiley.com/doi/10.1002/pon.1705/abstract¹⁴
- **Patient Concerns Inventory (PCI)**
patient-concerns-inventory.co.uk¹⁵

Tips on delivering an HNA care and support plan

The HNA questionnaire can be completed either on paper or digitally, which is known as Electronic Holistic Needs Assessment (eHNA).

You may want to consider the following before starting an HNA:

- Is the invitation letter worded clearly? You should explain how long the appointment will take and, if possible, who it will be with.
- What information will they need before the assessment to help them understand what to expect? Macmillan has a booklet to help people prepare for HNAs. It's available on Be.Macmillan (MAC12957_E04_N)
- What additional support may be needed e.g. language, vision and literacy (never assume everyone can read)?
- Do you have somewhere for people to complete their HNA questionnaire? Do you have somewhere for the supportive conversations? Finding a private spot is key as many of the questions can be personal and confidential
- Have you set a time frame for the appointment? For instance, explaining at the start how much time you have available helps set clear expectations and provides focus.
- Have you considered writing a short script that helps staff introduce the HNA?



Using a script to introduce the assessment may help set people at ease. Here are examples of HNA introduction scripts that can be adapted to each patient:

'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.'

'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 individual 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 people will open up as part of their HNA and that might be upsetting. People 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.

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 confidentiality.

For example, if there's a risk of a person harming themselves or others, do you know what you should do? A local policy and guidance will have been written to support staff, and it is essential that this is available to all undertaking the assessment and care planning process.

An HNA should focus on an individual and a one-to-one setting is usually best. Ideally the assessment should be completed by the person living with cancer. However, there are some exceptions:

Thinking about the types of support that might be needed

- 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, or 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 during the assessment and care planning process.

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

The purpose of the care plan is to support the people living with cancer and create a record of the conversation. Concerns should be described using the same language they 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, and the conversation that follows can be very emotional. This is why it's really important to find a quiet private space where the person isn't disturbed or called away.

If you are using Macmillan's eHNA you may want to consider:

- Asking the person to do the assessment at home as the assessment may be carried out on any device with an internet browser.
- Is there a tablet or similar device available at the time of the appointment?
- Can you connect to the Wi-Fi?

Writing the Care Plan

- Will there be a desktop PC or laptop to write up the care and support plan?
- Will this be written at the time of the care planning consultation or afterwards?
- If you are providing copies to the patient, is there a printer within easy reach?



Shez, Macmillan Neuro
Oncology Clinical Nurse

Training and skills required for HNAs

For experienced health and social care professionals, assessing needs is not a new skill. Using a validated HNA tool provides a structure for the assessment and identification of any support needs. The care plan then provides a record of the discussion and should include the actions needed for effective support. This document can then be shared across the care pathway as and when needed.

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.¹⁰

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 4.¹¹The Macmillan Competency Framework for Nurses (MCFN) Supporting People Affected by Cancer 2014 (update due in Autumn 2019) provides more information on the skills and the level of ability needed when caring for patients with a cancer diagnosis. It can help identify ways to improve skills. A 'skills-based competency framework' is currently in development (2019), highlighting the key skills needed by those supporting people living with cancer. This framework will cover the wider health and care workforce, including volunteers and support workers.

Those who will be supporting the HNA and or care planning process should consider the following training such as:

- Appropriate knowledge about cancer, cancer treatments and consequences
- Knowledge of where and how to signpost to appropriate support
- Screening for psychological distress
- Effective communication skills appropriate with the role and level of support being given (e.g., motivational interviewing/ coaching skills to support effective self -management, or Advanced Communication Skills and psychological support for psychological distress)
- Shadowing someone experienced at delivering HNA
- Macmillan online introduction to the recovery package and/or face to face understanding the Recovery Package if you are not familiar with this Macmillan's Explore (for new CNS or other HCP)
- SAGE and THYME – sageandthymetraining.org.uk

An HNA enables the person with cancer to identify issues that are important to them. It's important in supporting a personalised approach to assessment, care and support planning that the person is at the centre and is able to raise their issues, and that the care plan is shaped with them. Shared decision making and facilitating self-management are a core component of personalised care. This requires good communication skills, a facilitative approach and understanding what is important to the person and gives their life meaning, as well as being able to assess self-efficacy and what the person can do themselves and where they need support. This is a shift from a professionally led approach of assessment and care planning to allowing the conversation to be shaped by the person and ownership of their support plan.

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

Communication:

- An ability to empathise and communicate 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 concerns and know how to respond to them
- Allow people to explore their own support and 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 can sometimes make people feel a range of emotions that they've been keeping to themselves. It's important to remember that these emotions were there before your assessment and discussion began. 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 the person you are supporting 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 rather than simply telling them what to do. At the end of the assessment, particularly if it's been an emotional one, encourage the person to take stock of the past few minutes. You could try asking them what they're going to do with the rest of their day as this can help 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. If someone is thinking seriously 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 professional to feel anxious about confronting the issues at hand. But 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. 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. 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. Macmillan offer face to face well-being and emotional resilience courses for professionals on Learnzone at <https://learnzone.org.uk/macprofs/>

No matter what, if a person seems depressed, you shouldn't be afraid to refer them to a specialist. If the individual 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 confidentiality, but you do need to be open and honest with them about this (NMC Code of Professional Conduct 2015 [point 5.4]). It's also really important that you know and understand a person's condition and their full treatment and care history when providing the HNA.



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Consultant in Cancer and
Palliative Care, and Andrew

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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 or visit [macmillan.org.uk](https://www.macmillan.org.uk).**

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