Holistic Needs Assessment for people with cancer

A practical guide for healthcare professionals
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Foreword by the National Cancer Director

Holistic needs assessment should be part of every cancer patient’s care. It can make a huge difference to a patient’s overall experience and has the potential to improve outcomes by identifying and resolving issues quickly.

Undertaking an holistic needs assessment with the patient enables them to more fully engage in their care and facilitates choice. It enables the patient to take greater control of what happens to them and supports them to self-manage their condition. By helping patients identify their concerns teams will know where best to concentrate their effort and they will be able to develop a care plan that is tailored to an individual patient’s needs.

Holistic needs assessment is not a ‘one-off’ process and should continue through the patient journey into survivorship or end of life care pathways. There will be a requirement, incorporated into the peer review measures, to provide evidence that holistic needs assessment is being undertaken.

I would also encourage teams to look at the local results of the recent national cancer patient survey. These provide information about the experience of care for patients in individual trusts and with different cancer types. The findings can help to identify where improvements are most needed in the care pathway.

I hope you find this guide useful in helping to ensure all people with cancer are offered an holistic needs assessment.

Professor Sir Mike Richards, National Cancer Director
The importance of understanding the need for physical, psychological, social, spiritual and financial support for people with cancer and their carers was recognised in the NICE guidance devoted to improving supportive and palliative care for adults with cancer in 2004. It was reiterated in the Cancer Reform Strategy in 2007 and by the All Party Parliamentary Group in their report on inequalities in cancer published in December 2009. Improving quality of life and patient experience was a major focus in the improving outcomes strategy for cancer published in January 2011.

Guidance about the holistic assessment of the supportive and palliative care needs of people with cancer was published in 2007. It set out the main features of holistic assessment and provided direction and core content. Nearly all services are considering how best to ensure holistic needs assessment is effectively carried out and recorded but few have yet achieved widespread implementation.

Introduction

What is this guide for?
This guide builds on the previous guidance and adds further practical advice to help teams implement Holistic Needs Assessment (sometimes known as HNA) for all people with cancer; it complements but does not supersede the previous guidance. The aim of this guide is to provide more practical advice including some case studies to assist local teams with implementing HNA in day-to-day practice.

Who should read this guide?
This guide is aimed at all practitioners who will be involved in undertaking holistic needs assessment.
What is an Holistic Needs Assessment and why does it matter?

The term ‘holism’ comes from a Greek word meaning all, entire or whole. It is the idea that any given system cannot be explained by its component parts alone. Instead, the system as a whole determines how the parts behave.

In health and well-being holism is a philosophy that views the human as having physical, social, psychological and spiritual aspects of life, all of which are closely interconnected. An holistic assessment will consider all aspects of a person’s needs and that they are seen as a whole.

Undertaking an holistic needs assessment is not an end in itself. It is a means of ensuring that the person’s concerns or problems are in the first place identified so that attempts can be made to address them. It supports the broader aim of ensuring personalised care that reflects an individual’s health and care needs. An assessment should always result in a care, or action plan.

The assessment process can make a big difference to peoples’ experience of their care. It can help them realise that their concerns are worthy of consideration and not unusual. It opens the door for discussion. It brings to their attention sources of help they may not require there and then but may need at some later point. It may sometimes enable people to seek help at an earlier stage than they might otherwise have done, before the concern or issue has reached more serious proportions.

Part of the benefit of providing such support is to help people with cancer to make choices and to self manage their condition on a day-to-day basis. This should help to minimise the risk of a crisis which can lead to an emergency or unplanned admission.

A more consistent approach, through holistic needs assessment, of identifying those people whose needs are greatest and/or most immediate, enables teams and organisations to know where best to focus their efforts. It means that resources can be used more effectively and service needs identified.

Finally, it is not a one-off exercise. Holistic needs assessment carried out during the diagnosis and treatment phases should form the basis of assessment and care planning into survivorship or end of life care pathways.

In summary then, holistic needs assessment matters because it:

• Identifies people who need help
• Provides an opportunity for the person to think through their needs and, together with their healthcare professional, to make a plan about how to best meet these
• Helps people to self manage their condition
• Helps teams to target support and care efforts and work more efficiently by making appropriate and informed decisions
Getting started

Making sure that all people with cancer are offered an holistic needs assessment at key points in their cancer pathway requires teamwork. There is no ‘one-size-fits-all’ solution and your team will need to think about their preferred approach to ensure that the assessment process suits their patient group and fits with their existing processes to become a normal part of day-to-day practice.

Areas where holistic needs assessment is being introduced successfully have all started small, using one of the assessment tools which are already available (see the chapters on tools to support the assessment process and examples of practice).

Holistic needs assessment is not exclusively the role and responsibility of clinical nurse specialists. Other professional groups, including doctors, professionals allied to healthcare (AHPs), community nurses and social care professionals may be well placed to undertake part or all of the assessment. Clinical nurse specialists however often take a lead role in ensuring the assessment is undertaken, their experience and skills being well suited for this high impact intervention during the ‘on treatment’ phase.

To get started, spend some time discussing your approach amongst your team or service:

- Does everyone understand the idea of holistic needs assessment and why it needs to be done? Have any misconceptions been addressed? (see the chapter on myth busting)
- Look at your existing processes to see how the assessment process can build on these; try to avoid adding another ‘layer’ or gathering the same information more than once.
- Think about some of the practicalities – for example whether there is an existing IT system which you could adapt to record the results of the assessment, or whether a specially designed sticker might help the team to identify where assessment outcomes are recorded in patient notes.
- Look at your pathways and agree who is best placed to do the assessment at key points
- Consider whether all patients have enough time available with the person undertaking the assessment and if not what changes could be made to improve this.
- Decide on which tool you want to use to support the process (your cancer network may have recommended a specific approach and tool).
- Start small and have a go. Discuss how it went with the multi-disciplinary team (MDT) to get support and ideas about how best to ‘grow’ it in practice.

The key points have been defined as at diagnosis, at the start, during, and at the end of treatment, at each new episode of disease recurrence, the beginning of the end of life and at any other time that the patient may request. However if any of these key points follow one another quickly in time, unnecessary repeated assessments should be avoided.
Taking the time to do it

One of the most commonly heard concerns about undertaking holistic needs assessment is the lack of time to do it. A project was set up by the National Cancer Action Team (NCAT) in collaboration with the Central South Coast cancer network and Southampton University Hospitals NHS Trust to look in more depth at this issue and an external consultancy was engaged to undertake this work.

The work involved developing a clear understanding of the journey experienced by cancer patients by mapping the process from initial diagnosis through treatment and to follow up (initially with the gastro-intestinal cancer nursing team – covering oesophago-gastric, hepatopancreatobiliary (HPB) and colorectal cancer – and then with teams in urology and gynaecology). This involved interviews with stakeholders and gathering and analysing relevant statistics.

It was found that many aspects of the holistic needs assessment were already being conducted, but not formally recorded. There were also logistical issues such as having space in clinics and the locations of wards as well as a lack of understanding of how IT systems could help. But the main problem was that many ‘administrative tasks’ – for example chasing test results and chasing other information – were often completed by CNS staff. It was identified that across the team a full 2 days per week, on average, was spent this way.

The findings were then presented to senior decision makers. They were asked to support the implementation of HNA by releasing time spent by those who would be undertaking the assessment on non-value adding administrative work, for example by establishing necessary administrative support and adapting the Trust clinical information system to underpin the assessment process. The response was positive. Further work is underway to find others in the Trust (for example, MDT co-ordinators) who have capacity to take on the administrative work and to incorporate holistic needs assessment into the CNS’ job plans.

A report on this work will be available on the NCAT website by late Spring 2011.
Assessing needs should not be a new skill for most experienced health care professionals as many aspects of assessment are undertaken during the course of day to day practice. But Holistic Needs Assessment is about putting a structure and rigour in to the process of assessment to ensure all aspects, namely physical, social, psychological and spiritual aspects, of a person are considered. These aspects are sometimes referred to as the domains of assessment. Being able to undertake assessment in relation to some of these domains may require further training and support.

You need to prepare yourself so that you are confident about undertaking holistic needs assessment. You will need to know:

• how to communicate well,
• how to listen to and hear concerns and how to respond to them, allowing people to explore their own support and their own solutions
• what resources, information and support services are available for your patients.

If the person is undergoing active treatment, you should also have a good understanding of their condition and their treatment and care history.

Skills and knowledge to undertake holistic needs assessment

Communicating well

Good communication skills and particularly listening skills are a key requirement for any health care professional in direct contact with people with cancer. They are particularly important for undertaking holistic needs assessment as the conversation may lead to someone revealing very personal or intimate details.

There is much written elsewhere about communication skills which we will not attempt to cover again in this guide. You will already be aware of the need to establish a rapport with the person by showing respect and courtesy and demonstrating openness, kindness and sincerity. The assessment conversation should be a genuine human contact.

Most essential is that the person with cancer should be at the heart of the process; the assessment conversation should be approached as something you are doing with, rather than doing to, the individual, following their agenda, not yours. It means adopting a different role to the traditional “diagnoser and treater”. Remember that you are working with the individual to establish what concerns they have and how you might work collaboratively towards addressing them.

Training in advanced communications skills, such as the NHS Connected® programme, available to all core multi-disciplinary team (MDT) members, will enhance your communication skills and confidence. It involves the use of actors to enable you to practice difficult communication situations and to give you constructive feedback on your technique. Many cancer networks suggest this as a core requirement for all practitioners who undertake holistic needs assessment.

If you are unable to access the NHS Connected programme there are usually other communication skills training programmes available locally.
Listening and responding to concerns

As they tell you about their concerns and worries a patient may well become upset. This will be because there is an underlying cause which you may have brought to the surface by talking about their feelings rather than that you have caused the distress yourself. This emotional expression can be therapeutic in itself, so if you can, stay with the feelings first before gently encouraging the patient to consider what they, with your assistance, would like to do about the problem at hand.

The NICE Improving Outcomes Guidance describes a four-level model of psychological support for all patients with cancer and their families. This model suggests that staff at level 2, such as specialist nurses, doctors and allied health professionals, should be proficient in screening for psychological distress and intervening with techniques such as psycho-education and problem solving. Many cancer networks suggest level 2 skills as a core requirement for all practitioners who undertake holistic needs assessment.

There are some specific training programmes for detecting psychological distress already available such as that developed by Dr Kate Jenkins at Salisbury.

The National Cancer Survivorship Initiative are funding a level 3 ‘train the trainer’ programme from April 2011 so that each cancer network is equipped with a psychologist who can deliver the Salisbury training.

For further information contact Kate.Jenkins@salisbury.nhs.uk

Resources, information and support for patients

1 Some concerns may be resolved immediately (e.g. providing further information, prescribing an analgesic, enabling the patient to talk about the problem) or through a further consultation at a later date (if so, make a firm time for this).

2 Some concerns may be resolved through the patient taking responsibility for further action (becoming more socially active again, obtaining further information, speaking to their partner, attending a support group, taking more physical activity etc.)

3 Some concerns may require a referral to another service (other medical specialist, social worker, spiritual leader, clinical psychologist, specialist nurse, counsellor, rehabilitation professional etc).

Of course it is always possible that some problems may have been part of the patient’s life well before they had cancer and remain unresolved. In this case it is highly unlikely you will be able to find a resolution but the fact that you have heard and acknowledged the problem will be a supportive experience for the patient.
Knowing what resources and support services are available and how to access them is really important in order for you to be in the best position to support your patient’s needs. Make sure you know how to access information about local services for:

- Benefits advice
- Social care
- Employment advice
- Rehabilitation
- Financial advice (e.g. Citizens Advice Bureaux)
- Psychological support
- Support for spiritual needs (e.g. chaplaincy services and other faith leaders)
- Patient support groups
- Complementary therapies

Information for patients

The Information Prescriptions System (IPS) hosted by NHS Choices (www.nhs.uk/ips) aims to provide a ‘one-stop-shop’ of nationally developed information on all aspects of cancer and other long-term health conditions. During 2011, the Information Prescriptions System will contain information pathways for patients receiving palliative care and those who are approaching the end stages of their life. Pathways will also be developed for ‘Cancer Rehabilitation’ and ‘Living with Cancer’. As such, it will become an important resource when assessing an individual patient’s holistic needs and will enable access to information on a range of subjects including financial benefits, employment advice and so on.

On-line learning for practitioners

The e-Learning for Healthcare website (www.e-lfh.org.uk) hosts modules which are directly applicable to holistic needs assessment under the end of life care project. This is known as ‘End of Life Care for All’ or ‘e-ELCA’. The modules are both quality assured and peer-reviewed and aim to be as interactive as possible.

The way you access the e-ELCA modules depends on your role; further information about how to access is available at www.e-lfh.org.uk/projects/e-elca/register.html

You cannot learn how to assess patients by e-learning alone, but the on-line learning gives you the flexibility to check and update your knowledge at your own pace and wherever you can access the internet. Although the content of the e-ELCA modules is directed at those supporting people at end of life, the sessions for assessment were based on the same principles as for holistic needs assessment. Each session is designed to be standalone but you may find it more helpful to do some of these sessions sequentially rather than in a random order. The titles of the sessions are self-explanatory and you might like to start by looking at these sessions:
Suggestions for using the e-ELCA sessions

There are a number of different ways in which this resource can be used in combination with other training and guidance. Suggestions include:

- Use the sessions as a background context – eg. as a pre-requisite for face-to-face training or a foundation for further learning.

- Use the sessions for facilitated group learning and discussion. Used in a team format, the differences and nuances of how different wards/areas approach assessment could be teased out.

- Suggest more experienced staff use it as a ‘refresher’ – it is a good way of privately checking, and filling gaps in, knowledge.

- Less experienced staff can be asked to work through each session in more detail – there is a certificate available for each completed session.

- Focus on one specific module in anticipation of meeting a patient with specific needs – for example when you know that your patient has learning difficulties.

You might also want to look at these sessions to help inform your practices or in particular circumstances:

- Bereavement assessment and support
- Carer assessment and support
- Assessing through proxies
- Assessing those with fluctuating mental capacity
- Assessing urgent situations with limited information
- Assessment of the dying phase and after death
The use of an assessment tool can be an important part of holistic needs assessment to ensure consistency in considering all of the domains of assessment and in stimulating the assessment conversation. However an assessment tool is only one part of a holistic skill set; it should not become a ‘tick box’ exercise, nor should practitioners become a slave to the tool itself rather than focussing on the information it collects.

The main benefits of using a tool to support the assessment conversation are that:

- It ensures that the patient’s individual needs are the focus, not those which the healthcare professional undertaking the assessment thinks are the patient’s needs
- Used well, it provides a structure to the assessment conversation, enabling the patient’s concerns to be prioritised
- It ensures all areas of assessment are covered and not forgotten, or avoided
- It becomes familiar to the patient and can be administered by several different healthcare professional involved in their care

There are a number of tools that can support holistic needs assessment. These include, but are by no means restricted to:

- The Distress Thermometer
- The Pepsi-Cola aide-memoire
- The Sheffield Profile for Assessment and Referral for Care (SPARC)

Examples of each of these tools are included in the back of this booklet and the table which follows summarises some of their key features. These tools may be used separately or in combination (for example the Pepsi-cola aide memoire may also include use of the distress thermometer where indicated).

The distress thermometer and SPARC tool in particular lend themselves to enabling patients to self-assess. The advantage of this approach is that the assessment conversation can more quickly focus on issues of greatest concern. However care must be taken to ensure that the patient understands the purpose of the tool and that the language and presentation of the tool is both accessible and readable.
### End of life care

A needs assessment pathway is being developed for end of life care. It provides a guide to holistic assessment during the last year of life for all people, not just those with cancer. It suggests key points along the person’s journey when formal assessment may be required and maps nationally recognised needs assessment tools along the pathway, including the three tools listed above. It also suggests which tools may be most helpful at each point. A brief summary of each tool is provided and they can also be downloaded.

www.endoflifecareforadults.nhs.uk/tools/emerging-practice/needs-assessment-pathway

### Survivorship

The National Cancer Survivorship Initiative undertook testing of the assessment and care planning process during the summer of 2010 across 11 test sites in collaboration with NHS Improvement. In ten of the eleven test sites the distress thermometer was found to be a useful tool. A report on the evaluation of this work is available at www.ncsi.org.uk/assessment-care-planning

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<tr>
<th>Tool</th>
<th>Short description of the tool</th>
<th>Its origins and versions</th>
<th>Suitable for self-assessment?</th>
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<tr>
<td>SPARC</td>
<td>Explanatory paragraph plus 45 questions covering seven areas of potential need. For most questions, patients rate the degree to which they have been distressed or bothered by a symptom or issue in the past month using the responses; 0 ‘Not at all’, 1 ‘A little bit’, 2 ‘Quite a bit’ and 3 ‘Very much’</td>
<td>One version only – developed at Sheffield University as a screening measure to facilitate the referral of patients with advanced illnesses, regardless of diagnosis, to specialist palliative care.</td>
<td>Yes; in some areas it is posted out to patients before a clinic visit or used before a clinic appointment.</td>
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<tr>
<td>Distress thermometer</td>
<td>Image of a thermometer against which patients are asked to rate their overall distress level plus a problems/concerns check list which patients are asked to tick and then prioritise, using the thermometer to describe their level of concern.</td>
<td>The distress thermometer was developed by the National Comprehensive Cancer Network (NCCN) in the US. There are many versions of the problems / concerns checklist in use across cancer networks in England.</td>
<td>Yes; after the patient has been introduced to the tool for the first time in a face-to-face conversation in some areas it is posted out to patients at several other key points in their pathway to complete prior to the assessment conversation.</td>
</tr>
<tr>
<td>Pepsi-Cola aide memoire</td>
<td>An aide memoire based on the ‘pepsi-cola’ acronym (physical, emotional, personal, social support, information/communication, control, out of hours, living with your illness, after care) covering all points to consider in the assessment. It can also include brief information on resources and referral pathways.</td>
<td>Originating from the Gold Standards Framework, a systematic approach to supporting best practice for end of life care, the pepsi-cola acronym as an aide memoire remains as the original but additional information can be added locally.</td>
<td>No, the tool is an aide memoire and not in a format which patients could be asked to complete.</td>
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The assessment conversation itself is a high impact intervention. It should have a therapeutic value in its own right, though it is not a therapy session. This section gives some suggestions for structuring an assessment conversation along the lines of the Calgary-Cambridge model. We refer you to the Calgary-Cambridge website for additional information: www.gp-training.net/training/communication_skills/calgaryguide.htm

| Starting off | It's a good idea when you start the conversation to make it clear that this is a normal, routine assessment rather than something unusual. You should explain the purpose of the meeting and describe any paperwork you are using. Make sure your patient can see what you are writing on the assessment sheet if you are using one (or a screen if you have an electronic system available) – it should be a collaborative exercise and it is entirely up to the patient what is subsequently done as a result of your conversation. |
| Managing the assessment | Take time to talk about things more generally ("how have you been managing with the treatment?...") before expecting the patient to reveal more personal details. Concentrate on building a rapport and gaining their trust.

When discussing a concern move from the general to the specific. “You’ve put down insomnia. Can you tell me a bit more about this? What does your sleep pattern generally look like?... Okay, so what’s happening when you find yourself awake during the night?...”

Emphasise the patient’s own resources in managing their difficulties. “What do you think that’s about?... What do you think might be helpful in improving your sleeping?...” Acknowledge achievements and build on things that are going well.

Make it solution-focused rather than becoming bogged down with the problem itself. “Shall we move on now to what we might be able to do about this problem?” “What would be one thing that could be done to improve matters even slightly?”

Focus in on the main concerns – don’t attempt to find solutions to everything. If a patient has lots of concerns do acknowledge them and don’t try to skip over some but do be firm about the amount of time you have available. “look you have identified a lot of concerns. We only have a x minutes of time available today, which of these would you like to focus on today” |
| Wrapping up | Summarise what you have discussed and what steps, if any, you will take (e.g. referral) and those that the patient has agreed to take. Record what you have agreed to do in a care (or action) plan (more about this later). If a referral is to be made, be sure that you have obtained the patient’s permission for this to go ahead.

Thank the patient and ask them if they are comfortable with the summary sheet being placed in their medical case notes or kept on the computer system. Offer them a copy of the summary sheet or assessment tool if you have used one and the care plan.

Do bear in mind that it is not the aim to try to solve all your patient's problems there and then. For example, if someone confides in you that they are living in poor housing conditions there may be little you can do about that (though you might be able to offer, with their permission, an onward referral to other services). But the very fact that you have listened and heard their story will release some of the person’s anxieties ("they now know what I have to deal with") and help you to understand what they have to cope with ("I now know what that person is facing").

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Information on the Calgary-Cambridge method is available at www.gp-training.net/training/communication_skills/calgaryguide.htm
Preparing for an assessment

The preceding sections looked at the skills and knowledge you need to be confident in doing a good assessment. There are also some more practical things that you will need to think about each time you carry out an assessment. Here is a suggested check-list:

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<tr>
<th>Preparing yourself</th>
<th>Check?</th>
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<tbody>
<tr>
<td>Is there a quiet room you can use where you will not be disturbed?</td>
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<tr>
<td>Have you looked through any other relevant information already gathered about the patient?</td>
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<tr>
<td>Do you have a copy of any previous assessment(s) undertaken, or a self-assessment if the patient has completed one?</td>
<td></td>
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<tr>
<td>Do you have a copy of the assessment tool you are using?</td>
<td></td>
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<tr>
<td>Do you have any other materials you might need – such as stationery to record the conversation for the patient?</td>
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<tr>
<th>Helping to prepare your patient</th>
<th>Check?</th>
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<tbody>
<tr>
<td>If you are using self-assessment as part of the process, have you given the patient the self-assessment form with accompanying instructions or explanation ahead of the assessment conversation?</td>
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<tr>
<td>Have you warned the patient beforehand about the expected duration of their appointment with you in case they need to make appropriate arrangements (e.g. transport)?</td>
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<tr>
<td>Have you thought about whether the patient will be able to manage the time required for the assessment? If you think they might struggle, try to split the time over more than one session if this is possible.</td>
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<tr>
<td>Have you explained the purpose of the assessment to the patient? There is a patient information leaflet available from Macmillan describing the assessment and care planning process which you might find helpful to give the patient before you meet.</td>
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<tr>
<td>Are they likely to need any additional support (such as an interpreter for someone whose first language is not English, a care worker for someone with special needs, a sign language interpreter for someone who is deaf and so on), or would they like to ask a carer, friend or relative to be with them?</td>
<td></td>
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<tr>
<td>Do they need to bring their reading spectacles?</td>
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Ideally an holistic needs assessment should be done with the patient alone in order that they are comfortable discussing any of their concerns, but there may be exceptions such as if they need additional support such as an interpreter (someone not related) or sometimes someone may just want the support of a carer, friend or relative. In all cases, be aware of the patient’s own needs and circumstances.

Remember not to be slavish to the form or tool you use for your assessment. For some patients you might not be able to get through all of the assessment in one go or you might want to change the order in which you go through it.
Every assessment should result in a care, or action plan. In simple terms this is a summary of the issues and concerns which were identified and the actions or care jointly agreed to address those concerns. Again, as before, this is nothing new as you will be used to recording many aspects of the care you give.

The care plan should be written with the involvement of the person and seen as belonging to them. It can be a written document, an electronic document or both – you will need to decide locally where the best place is to store it (e.g. in case notes). It should:

- be patient- and family/carer-centred
- focus on the needs identified by the patient
- be shown or read to the patient
- include a record of whether the patient is willing for the information to be shared with others
- be available for the patient to take away with them, unless they express a wish not to do so.

The better the record of the assessment, the more effective can be the teamwork involved in the person’s care. There are clear benefits to documenting the assessment in a standard and easily accessible format of an action or care plan. It helps to ensure that the person’s needs are both identified and addressed. It also helps other members of the multi-disciplinary team to easily identify when and how much of the holistic needs assessment has been undertaken and what actions or care have been agreed.

Writing things down in a care plan may help the patient achieve better health outcomes. For example they may be less anxious about what is going to happen and less likely to need repeated GP appointments or emergency admissions. Crisis planning and knowing whom to contact can reduce unplanned admissions. Having a care plan helps people know how to manage their condition and they can share this with their family, should they so wish.

Features of a care plan

The care plan should convey the real needs of the patient and what actions have been agreed to plan to meet those needs. The level of detail needed is a balance between ensuring there is enough information so that others don’t need to ask the same questions of the patient and not documenting every last detail so as to make the process too onerous and time-consuming. There is no hard and fast structure for a care plan but at minimum it should contain:

- The patient’s name and identifying information
- Name of the healthcare professional who undertook the assessment and the date it was done
- A description of the patient’s key concerns or needs
- Agreed actions to help address the key needs (this may include a note of any services or support already in place)
- Information to help the patient know who to contact for more help or if a problem should arise
- A record of whether the patient has agreed to this information being shared with other health and social care professionals.
Sharing assessment information

Communicating the outcome of assessments and coordinating care to address identified needs is part of the process of assessment. The outcome of an assessment should be shared, as effectively as possible and with the patient’s consent, with the multi-professional team involved in their care such as their:

- GP
- District Nurse
- Social Care Team
- Hospital consultant including Specialist Palliative Care Team or other teams involved in the patient’s care
- Allied Health Professionals
- Hospice or community palliative care team
- Social Worker
- Welfare Rights / Benefit Advisor

It can sometimes however be quite a challenge to do this efficiently as different organisations, and different teams within organisations often operate different systems, be they electronic or paper based. This can mean that the same information needs to be recorded more than once or re-keyed onto another computer system. Given these limitations, practical solutions – unlikely to be perfect – need to be tried. For example in some areas a sticker system is used in patient notes to indicate that an assessment has been undertaken, by whom and on what date. Others use a front page ‘tracker sheet’ to track which bits of the assessment have been completed.

There is advantage to be gained therefore by agreeing a common approach and common paperwork across a locality or network; even if the same assessment tool is not used, having a common format for sharing the outcome helps more efficient communications.

The key worker assigned to the patient may well be the same person who has undertaken the assessment, but if not they should be involved in ensuring the outcome of the assessment is shared appropriately with other health and social care professionals. This information should be one of the main things which is handed over whenever the key worker role is handed on.
The essence of holistic needs assessment is about you, as a healthcare professional, truly engaging with your patients, encouraging their input and views about their condition and finding out what could really make a difference to support them. You will know on an individual level when this is happening. There are also some different sources of information that can be collected to help your team or service assess the effectiveness of their approach by checking (a) whether the holistic needs assessment process is being undertaken and (b) what effect it has.

**Audit**

Audits are a good way of showing whether HNA is being undertaken. A common audit tool across a locality would be preferable though it is recognised that the practicalities of this can be difficult. Where electronic recording of HNA is possible the task is much easier, but otherwise there needs to be some mechanism in patient notes to help identification of the HNA having been done. Use of a common form or pre-printed stickers as mentioned earlier or a standard format care plan may support this.

**Patient experience**

Information from surveys of patients can help give an indication of the effect of undertaking holistic needs assessment and can be a useful way of finding out how successful the implementation of things like the key worker role and the holistic assessment have been in your team, hospital or network. There is no straightforward way of asking patients whether they had an assessment in a survey question format but you can piece together different bits of information which will give you an indication of whether different aspects of their needs were considered and hence the effect of the assessment process. In the recent national survey of people with cancer the following questions relate to aspects of holistic needs assessment.
Figure 1: National Cancer Patient Experience Survey findings. The survey was carried out in the first three months of 2010 and the national report published in December 2010. 67,713 patients responded to the survey giving a response rate of 67%.

<table>
<thead>
<tr>
<th>Survey question</th>
<th>Overall findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did hospital staff give you information about support or self-help groups for people with cancer?</td>
<td>Of those patients who said it was necessary, 79% reported having been given information about support or self-help groups for people with cancer by hospital staff. 21% said they did not get any information but would have liked some.</td>
</tr>
<tr>
<td>Did hospital staff give you information about how to get financial help or benefits?</td>
<td>Of those patients who said it was necessary, 50% said they had been given information about how to get financial help or benefits by hospital staff. 50% said they did not get any information but would have liked some.</td>
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<tr>
<td>While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?</td>
<td>Of those patients needing emotional support, 71% said they were definitely given enough emotional support from hospital staff; 22% said they were to some extent. 7% said they would have liked more support.</td>
</tr>
<tr>
<td>Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?</td>
<td>61% of patients said that the different people treating and caring for them always worked well together to give the best possible care; a further 29% said they did so most of the time. 8% said they only did so some of the time and 1% said they never did.</td>
</tr>
<tr>
<td>Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year, did you feel like that?</td>
<td>80% of patients said that they did not feel that they were treated as “a set of symptoms” rather than a whole person over the last year; 16% said they sometimes felt this and 4% said they often felt this way.</td>
</tr>
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</table>

Reports from the national survey are available by trust<sup>8</sup>, and where numbers allow comparisons are available by tumour group within Trusts. This information should be used to look at where there might be gaps in support. The recently published <i>Improving Outcomes: A Strategy for Cancer<sup>9</sup></i> stated a commitment by the Department of Health to repeating the cancer patient experience survey.

**Other feedback from patients**

More subjectively, patient focus groups, user groups or support groups may be a useful source of information about what it feels like in practice from a patient’s, relative’s or carer’s perspective. This feedback should be interpreted with care but useful comparisons with information gleaned from surveys may be possible.

Other sources of patient feedback include complaints, most of which are as a result of breakdown in communications. There may, for example, be complaints which can be related (directly or indirectly) to a lack of understanding on behalf of the professionals of the patients’ issues or concerns. Whilst this information cannot prove either way whether HNA is being undertaken it may be a useful check of whether there are some common themes which undertaking HNA could address.

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<sup>8</sup> The overall and Trust level reports are available from: http://www.dh.gov.uk/en/Healthcare/Cancer/Patientexperience/index.htm

Myth-busting

<table>
<thead>
<tr>
<th>Things people often say...</th>
<th>Our response...</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I don’t need to do HNA as I already know which patients need help”</td>
<td>In other areas where very experienced healthcare professionals have started to use holistic needs assessment they were surprised at the issues uncovered. Some patients and carers who appeared to be coping well on the outside had really major concerns which they hadn’t talked about. They were not things which the healthcare professionals had anticipated. As well as this it is important that you are able to share with other members of the team what that person’s needs are and what actions you have taken to address their concerns.</td>
</tr>
<tr>
<td>“Not everyone with cancer needs an holistic needs assessment – it’s only for people who need palliative care.”</td>
<td>You don’t know this for sure if you don’t ask. All patients with cancer and their carers should be offered the opportunity for an holistic needs assessment at least once, though not everyone will want to have the assessment conversation. Patients are also entitled to ask for an assessment.</td>
</tr>
<tr>
<td>“It’s going to take a long time every time I do it and I don’t have the time”</td>
<td>It might not take as long as you think (the study in Bristol using the distress thermometer tool recorded an average time of 16 minutes per assessment). Others have also said that using a tool such as SPARC or the distress thermometer helps to structure the conversation and gives you a way of focussing on the most important issues for those patients who tend to take a lot of your time anyway.</td>
</tr>
<tr>
<td>“I don’t like the tool we are supposed to use, it feels like more paperwork and yet another ‘tick-box’ exercise”</td>
<td>It’s important you don’t become a slave to the tool. It’s there to help you make sure you cover all the areas which should be included in the assessment and that there’s some record of you having done that. It’s very definitely NOT a tick-box exercise so far as the patients are concerned. It’s a highly valued part of the care you give.</td>
</tr>
<tr>
<td>“I already do HNA but just don’t follow the exact tools and guidance which my network has sent out”</td>
<td>Great. But ask yourself if you really do cover all the domains and not just the ones you are most comfortable with. And you do need to record the outcome so that unmet needs are identified and in case there are any problems or complaints in the future for example. It should not be a showstopper if you don’t use the same tool but it would help the teamwork if you record the outcomes (in an action or care plan) in the same way.</td>
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Examples of practice

Examples of where holistic needs assessment is being introduced are in evidence around the country. There is no single perfect solution but many examples of innovative work in moving towards HNA being part of day to day practice. Some examples of these are offered in this section.

Model 1: Nottingham University Hospitals NHS Trust

Key points

- Patients with lung cancer have their needs assessed by the cancer nurse specialist or a member of the rehabilitation team using the SPARC tool
- Further assessment or support needs based on the patients’ responses to the SPARC tool are discussed and agreed at the weekly multi-disciplinary team meetings

A Macmillan Cancer Support 3-year project grant is providing a pro-active rehabilitation service for people with lung cancer, consisting of a dietician, occupational therapist, physiotherapist and data manager. The service works closely with, and is supported by, existing thoracic cancer and specialist palliative care services.

The Sheffield Profile for Assessment and Referral for Care (SPARC) questionnaire is routinely used to screen for supportive and palliative care needs at the time of diagnosis. An initial survey of 100 patients had established that the SPARC was acceptable in this setting, with questionnaires completed by the patient alone, or with the aid of a member of staff or carer in 65, 22 and eight instances respectively.

Either a member of the rehabilitation service or a lung cancer nurse specialist invites the patient to complete the SPARC. This is generally 1–4 weeks after being informed of their diagnosis at their next visit to hospital, e.g. for an investigation or outpatient review. For those patients with no planned visits within this time frame, following telephone contact, a SPARC is posted out with a stamped addressed envelope.

The SPARC questionnaire begins with an explanatory paragraph and contains 45 questions with 56 possible responses covering seven areas of potential need. For most questions, patients rate the degree to which they have been distressed or bothered by a symptom or issue in the past month using the responses; 0 ‘Not at all’, 1 ‘A little bit’, 2 ‘Quite a bit’ and 3 ‘Very much’. Generally, the SPARC takes about 15 minutes to complete and, according to patient preference, it can be completed during the visit, or at home (SAE provided). Experience in non-English speaking patients is limited; however, it has been successfully completed with the use of translators.

The results of the SPARC are then discussed at a weekly multidisciplinary meeting attended by the members of the rehabilitation service, lung cancer nurse specialists and a consultant in palliative medicine. All patients are assessed by the dietician. Generally, patients scoring ‘Quite a bit’ or ‘Very much’ in particular issues will also be contacted for further assessment by the appropriate team member.

Continued overleaf
It is hoped that greater understanding of the needs of people with lung cancer and the provision of better support from the time of diagnosis will have the potential to improve the overall experience of care, optimize independence, quality of life and to help them to remain in their preferred place of care.

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Model 2: Doncaster and Bassetlaw Hospitals NHS Foundation Trust

Key points
- The SPARC tool is being used for self-assessment prior to having the assessment ‘conversation’ and is posted out to patients prior to a clinic or home visit, or given during clinic
- Healthcare assistants are able to help patients to complete the questionnaire
- Different teams are tailoring the process according to how best they feel it fits with their patient group

At Doncaster and Bassetlaw NHS Trust\(^{10}\), the Sheffield Profile for Assessment and Referral for Care (SPARC) tool is being rolled out to support the holistic needs assessment process.

Self assessment using the SPARC tool is the first part of a three step process, and is followed by the assessment ‘conversation’ held between the cancer specialist nurse and patient and the action plan which is agreed together.

The project has been going since September 2009 and to get started, teams have agreed to carry out the holistic needs assessment at least once for all patients with cancer. The trust has not been prescriptive about exactly when the assessment should take place and different teams are tailoring the process according to how best they feel it fits with their patient group though in all cases the assessment is never carried out at the same time that the patient receives their diagnosis.

\(^{10}\) Doncaster NHS trust is a large acute trust comprising of five hospitals, four of which have in-patient beds, serving a population of 400,000. There are around 26 specialist nurses for cancer.
• It was found that the main concerns recorded by patients were centred on their surgery when the SPARC questionnaire was used for colorectal patients during a hospital stay. When used during outpatient consultations a wider range of concerns were elicited covering psychological, social and spiritual issues. All teams now only use the questionnaire for outpatients.

• Teams looking after patients with cancer of the breast, lung or head and neck and those with a stoma carry out home visits and the assessment is done during one of these visits. The SPARC questionnaire is posted out to the patient a few days before the visit, along with an accompanying letter.

• Other patients are invited to complete the SPARC questionnaire during a clinic visit (in some cases the questionnaire and letter are posted to the patients a few days before their clinic visit). Healthcare Assistants are being involved to assist patients complete the questionnaire, for example with reading questions and helping them to write on the form, but it is always a clinical nurse specialist who carries out the assessment conversation.

• The Lung CNS have set up a nurse led clinic to allow more time to explain and support patients after their diagnosis and treatment plan, or if a patient has additional concerns, symptoms that need to be addressed. This is an ideal opportunity to use the HNA process.

The assessment is something which is considered a core part of the specialist nursing role. The SPARC tool and process gives the assessment process a structure and use of the same tool across the trust means it is easy to identify that the assessment has been undertaken. Despite the questionnaire enabling the assessment conversation to focus on issues of greatest concern, the process does take time, the amount of time being variable depending on the patient and the complexity of the issues raised. The accompanying guidance gives permission for nurses to say “I’ve only got 20 minutes…” or “I can talk about x issue but will ask y person to follow up with the other things”.

The trust has developed a sticker which is inserted into the patient’s notes following the assessment. The action plan form is very simple, identifying the main issues and actions which have been agreed. As well as a copy being given to the patient and included in their notes, copies of the action plan are also sent to the patient’s own GP and to any services to which the patient is referred.

The trust recognises that the process of ensuring that all patients with cancer are assessed holistically is only just beginning – for example only the more complex breast and urology cancer patients currently receive an assessment – but the intention is to develop the use and spread of the SPARC tool and assessment process over time encompassing staff in primary care, particularly the district nurses. The local hospice is beginning to use the tool for their day-care patients and the trust is keen to develop the process to support follow-up care as part of the wider survivorship agenda.

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The breast care clinical nurse specialists at Sunderland felt that their practice of having a post-operative session with patients on the ward was not as effective as they wanted and for more than a year now have moved the session ‘upstream’ and now carry out a pre-operative counselling session instead with all their patients.

The appointment is scheduled in the hour before the pre-operative assessment clinic and happens very soon after the patient has first received their diagnosis. It is at this stage that the distress thermometer is used to structure the counselling session. The tool is introduced and the nurses talk through how it is used.

The nurses have observed that the concerns which are identified soon after diagnosis are usually those listed on the right hand column on the page – concerns around physical effects, independence and appearance. By the end of treatment the concerns tend to move across to those listed in the left hand column and focus more on social and emotional wellbeing as well as spiritual issues.

Partners are encouraged to attend at the pre-operative counselling session and often prompt the patient to be more assertive about some of the worries they have expressed privately. Although the nurses always offer the patient a copy of the completed distress thermometer tool to take home, many do not wish to have a copy.

A copy of the results from each time is kept in the nursing notes and a summary documented on the Trust’s hospital information system.

The distress thermometer is then used a number of times during the course of the patient’s treatment both by the breast care nurses at the monthly chemotherapy/Herceptin drop-in sessions and by the chemo nurses during treatment sessions.

When patients come to the end of their treatment, by now they are very familiar with using the distress thermometer tool and it is posted out to them two weeks before their end of treatment workshop, again two to four weeks after this workshop and then again six months later when they are invited to attend a ‘moving on’ group.

The aim of these workshops is to help patients to take greater control of their lives, promoting good health and self-management. Patients seem to experience a peak in anxiety around the end of their treatment and are often more vulnerable as the safety net of regular hospital visits are dramatically reduced. The nurses feel it is vitally important patients are assessed with the distress thermometer at the end of treatment so any distress

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**Examples of practice**

**Model 3: City Hospitals Sunderland NHS Foundation Trust**

**Key points**

- Led by their patients’ needs, rather than those of the consultants, the CNSs have re-structured their contact time with their patients in order to introduce a pre-operative counselling session
- The distress thermometer is used to structure the holistic needs assessment at several times during the patient pathway
- As well as being used during and at the end of treatment the distress thermometer is also being used at post treatment and ‘moving on’ workshops, the points at which patients often seem more vulnerable as the safety net of regular hospital visits are dramatically reduced
can be highlighted and interventions agreed.
In addition to all this a reconstruction workshop is also offered and a ‘walk and talk’ session has been introduced inviting cancer survivors on a 2 hour Sunday morning jaunt!

The nurses were apprehensive about using the distress thermometer at first but gave it a go and soon realised that it can give a useful structure to what is, after all, good nursing practice. Some patients do require much more time spent during the assessment conversation, but the nurses feel that they would have required that whether or not the tool was being used. In fact, for these people the DT can help structure the conversation and enables the nurses to focus their patients on their more pressing concerns.

One training session was felt sufficient before starting to use the distress thermometer in practice. Learning to adapt to the changes needed to embed this process into day-to-day practice was however not always easy – it took a while to introduce the pre-operative assessment and to find the best point at which to introduce the distress thermometer. But the benefits which this gave to the patients were quick to become apparent and provided enough encouragement and incentive to carry on using the tool.

In summary, points on the pathway when the distress thermometer (DT) is used at Sunderland are:

1 At pre-operative counselling the DT is first introduced to the patient
2 The DT is used regularly at the breast care nurses monthly Chemotherapy and Herceptin drop in sessions.
3 Two weeks before the End of Treatment Workshop the DT is posted to patients and they are asked to bring their completed DT with them to the workshop session; between two and four weeks after the session another DT is posted to patients which they are asked to post back.
4 It is posted again to the patient two weeks before they attend a ‘moving on’ group which is held 6 months following the end of their treatment
5 Any concerns highlighted at any stage are signposted to complementary services as appropriate.

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Related information:
Macmillan Voice, Winter 2009 Helping women cope following breast cancer treatment
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SPARC: Professor Sam Ahmedzi, Professor of Palliative Medicine, Academic Unit of Supportive Care, School of Medicine and Biomedical Sciences, University of Sheffield. For an electronic version of this document contact pallmed@sheffield.ac.uk

Pepsi-Cola aide memoire: Jackie Tritton, Nurse Director, Mount Vernon cancer network

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Related websites

National Cancer Action Team (NCAT)  
www.ncat.nhs.uk

National Cancer Survivorship Initiative (NCSI)  
www.ncsi.org.uk

End of life care  
www.endoflifecareforadults.nhs.uk

National cancer patient experience survey  
– National report  

National cancer patient experience survey  
– Trust level reports  
www.quality-health.co.uk/cancer-reports

National Cancer Peer Review Programme  
www.cquins.nhs.uk

Connected© (National communication skills training)  
www.connected.nhs.uk

Patient Experience/Cancer Information Pathways  
www.cancerinfo.nhs.uk

Information Prescriptions  
www.nhs.uk/ips