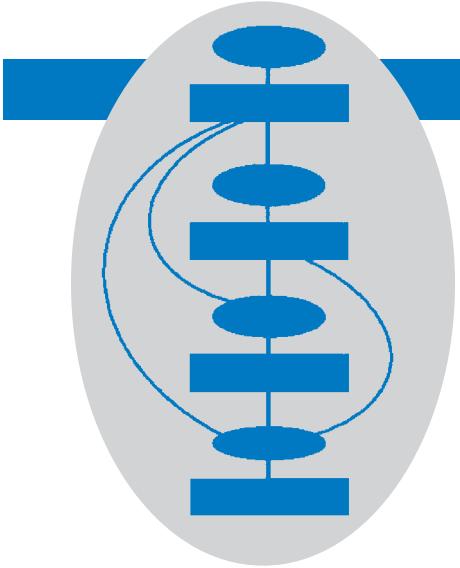

NHS

National Institute for Clinical Excellence

Supportive and palliative care services for adults with cancer

Understanding NICE guidance – information for adults with cancer, their families and carers, and the public

Introduction

From the moment someone is diagnosed with cancer, their world is very much changed. Their priorities change and their principal concern is to obtain treatment quickly. Although people are living longer than ever with cancer, diagnosis can bring great anxiety and a sense of loss of control. This means that patients and their families need good information and a lot of support. These needs start with the first thought of cancer, and continue when people go for tests, get a firm diagnosis, have treatment and find themselves living with the impact of the disease. The need for support can become even greater if a person is close to death or, for families and other carers, if someone has died.

Supportive and palliative care is about providing support at all stages of a person's experience with cancer. Supportive care means helping patients and their families cope with cancer and its treatment. Palliative care means alleviating pain and discomfort to improve a person's quality of life when it's not possible to cure the cancer. This support and care comes from the NHS, social services and a wide range of voluntary organisations. People affected by cancer, and their family and friends, can also meet many needs themselves.

The National Institute for Clinical Excellence (known as NICE) has issued guidance (recommendations) on supportive and palliative care services. The guidance advises those who develop and deliver cancer services for adults with cancer about what is needed to make sure that patients, and their families and carers, are well informed, cared for and supported. The recommendations also stress the importance of:

- responding to the individual needs of people affected by cancer
- recognising the central role of families and their potential need for support
- recognising that patients have different needs at different times during their illness
- valuing the knowledge, skills and resources that patients and their families already have, enabling them to contribute to their own care and support
- involving patients in the planning of services
- making sure services take account of people's backgrounds and culture and are accessible to people with disabilities.

NICE has recommended that, in each 'cancer network', key people should be made responsible for making sure the recommendations are put into practice. (A 'cancer network' is a partnership of organisations, professionals and patients and carers within a local area.)

This is a very shortened version of NICE's guidance, summarising the key recommendations. It is intended both for people affected by cancer and for the wider public, and it was developed in close consultation with people living with cancer, as well as health and social care professionals. The full version (*Cancer Service Guidance – Improving Supportive and Palliative Care for Adults with Cancer*) is available from the NICE website (www.nice.org.uk).

Summary of key recommendations

This is a summary of the points covered by the 20 key recommendations in the full version of the NICE guidance.

People affected by cancer should be involved in developing cancer services

People affected by cancer, and their carers, can make an important contribution to the development and delivery of services because they know from first-hand experience what is needed. NICE recommends that there should be systems in place to make sure that people who use cancer services are encouraged to make their voices heard in a variety of ways. Some may wish to give comments on their individual experiences of whether cancer services met their needs, so that improvements can be made where necessary. Others may seek to become involved in developing cancer services, by becoming members of local NHS committees or groups, including Cancer Partnership Groups. Some may also wish to help with studies on whether services meet patients' and carers' needs, so that changes can be made where necessary.

There should be good communication, and people affected by cancer should be involved in decision making

Learning that you have cancer has a major impact both on a patient and on their family and other carers. The NICE guidance recommends that, wherever possible, this information should be given by a senior health professional who is trained in giving this sort of news. Patients need to be able to talk through their own circumstances and express their views about both initial treatment and subsequent care. The guidance recommends that all significant discussions should be recorded in a patient's notes and the patient should be offered a record of key points.

Patients are often concerned about a lack of coordination between the many doctors, nurses and other professionals involved in their care, whether in hospital, a hospice or in the community. They can find it extremely irritating – and sometimes distressing – to be asked to repeat their story yet again. NICE recommends that there should be processes in place to make sure that all healthcare professionals involved in a patient's care inform each other about developments affecting that patient and work together to provide coordinated care. Also, patients and carers need to know who to contact and how to obtain the help they need. The NICE guidance says there may be benefits in appointing a 'key worker' whom patients and carers can contact and who is familiar with the planned treatment and care.

Information should be available, free of charge

People with cancer cannot be fully involved in decisions about their treatment and care if they are not well informed. Most patients want to learn about their particular cancer, possible treatments, and the full range of support available to them, including telephone helplines, self-help organisations and complementary therapies.

NICE recommends that patients and carers should have easy access to a range of high-quality materials providing information about cancer and cancer services. This information should be offered routinely both at initial diagnosis and at other significant points and staff should offer to discuss the information with people in the light of their individual circumstances. Information is part of a patient's treatment and should always be free of charge. Every local area should have information policies, developed with people affected by cancer.

People affected by cancer should be offered a range of physical, emotional, spiritual and social support

Patients with cancer, and their families, will have a range of needs for support. Feeling emotionally upset is a natural and understandable reaction to a life-threatening disease, as is questioning the meaning and purpose of life. A diagnosis of cancer may have an impact on the whole of a person's life, including relationships with family and friends, employment and finances, and the ability to carry

out personal care. Although many people are able to meet these needs themselves, there may be times when they need additional help.

NICE recommends that there should be arrangements to provide practical help for patients and their families – for instance, advice on employment issues or state benefits, or help with personal care or cleaning or shopping. The guidance says that clear agreements should be set up between health services, social services and voluntary organisations to make sure this kind of help is provided when it's needed. Healthcare professionals also need to be aware of potential needs for physical, psychological, spiritual or emotional support. The guidance recommends that patients and carers should regularly be asked about their needs at key stages, including on diagnosis, at the beginning and end of treatment or after a recurrence of cancer. This information should be noted in the patient's records. It should then be the responsibility of professionals to make sure people get the help they need, when they need it, whether people are being cared for in their own home, a care home, a hospice or hospital.

People can get great benefit from talking to others in the same situation. Self-help and support groups, as well as other peer-to-peer support schemes, offer an opportunity to gain practical advice and share experiences with others. They are important in enabling people to give – as well as to receive – help. NICE recommends that those providing services should discuss opportunities for such involvement with patients.

People with cancer may also need assistance with symptom management, either regularly or from time to time. Those working with patients should assess their needs for help with a broad range of symptoms, such as pain, fatigue or breathlessness, and set up a plan to manage these.

The NICE guidance says that organisations providing healthcare should work in partnership with voluntary organisations to decide how best to provide complementary therapies where there is evidence that supports their use. At the very least, they should provide good quality information. Each cancer network (see page 1) should have policies for good practice for the complementary therapies it has decided to make available and healthcare providers should make sure that treatment is carried out in line with these policies.

There should be services to help people living with the after-effects of cancer manage these for themselves

People are living increasingly longer after treatment, but cancer and its treatment can have a major impact on the ability of some people to lead a normal life. Some activities that others take for granted, such as speaking, moving around, eating or drinking, can be severely impaired by the disease and/or its treatment. Cancer rehabilitation services support patients in dealing with these kinds of difficulties. They are provided by a range of professionals within the NHS, such as physiotherapists and dieticians, and by relevant voluntary organisations.

NICE recommends that all areas should ensure that there are systems in place to regularly assess patients' needs and that comprehensive rehabilitation services and suitable equipment are available.

People with advanced cancer should have access to a range of services to improve their quality of life

People who have advanced cancer and for whom a cure is no longer possible want to ensure that they have the best quality of life. Patients and their carers can find that needs change very quickly, so that services must be able to respond flexibly to provide help and support.

The NICE guidance says there should be systems in place to assess the needs of people with advanced cancer. Medical and nursing services should be available 24 hours a day, 7 days a week. Equipment should be provided without undue delay. Although this support is normally provided by a GP or district nurse, some people will have particular difficulties that require specialist palliative care services, for example, for the control of pain. There should be a range of specialist services, suitable to meet the needs of local people. Doctors or nurses who are not specialists in palliative care should be able to obtain specialist advice, 24 hours a day, to help them meet the needs of a patient.

There should be support for people dying from cancer

People who are dying from cancer and their families have particular needs. The NICE guidance says that these should be identified and addressed by those providing their care, whether it be in the patient's own home or in a hospital, care home or hospice. For example, people's preferences about their place of care and death should be supported, where possible.

The needs of family and other carers of people with cancer should be met

Cancer does not only affect the patient. It can also have a devastating impact on the whole family and close friends. They are often the people who provide essential day-to-day support and practical assistance, but their own needs for emotional and practical support may go unrecognised – often because they put the needs of the patient first. Professionals should ask family members and other carers about their own needs, particularly at crucial times such as diagnosis, recurrence of cancer, or death. These might include needs for information, for talking to someone in the same situation or for a break.

The NICE guidance recommends that in every local area, there should be organisational arrangements for developing and delivering services for families and other carers, and this should include support for families and carers after someone has died.

There should be a trained workforce to provide services

The NICE guidance says that each cancer network (see page 1) should assess and meet local needs for staff, in terms of their number, type and level of training. Suitable education and training programmes should be available to provide professionals with the knowledge and skills that they need.

Further information

It is important to remember that your local services may be a little different from those described here – the supportive and palliative care guidance sets out ways that services should develop over the coming years.

If you or someone you care for has cancer and you have questions about the information here, talk to your GP, community nurse, consultant or specialist nurse or organisations providing cancer information and support. Information about cancer and about patient support organisations is available from NHS Direct (telephone 0845 46 47 or go to www.nhsdirect.nhs.uk).

If you or someone you care for would like to become involved in planning or commenting on cancer services, do speak to a local health professional or contact a patient support organisation.

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Copies of this document can be obtained from the NHS Response Line by telephoning 0870 1555 455 and quoting reference number N0476. The full guidance, reference number N0474, has also been published and a CD with all documentation including the research evidence on which the guidance is based is available, reference number N0475. The Executive Summary, *Guidance on Cancer Services – Improving Supportive and Palliative Care for Adults with Cancer: Executive Summary*, is also available, reference number N0477.

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