

# DRAFT FOR 2<sup>ND</sup> CONSULTATION

## Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer

### Public Version

#### Introduction

From the moment someone is first diagnosed with cancer, their world is very much changed. Former priorities fade and the 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. Starting with the first thought of cancer, these needs continue when people go for tests, get a firm diagnosis, obtain treatment and find themselves living with its impact. They 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 the provision of all such support. This support comes from the NHS, social services and a wide range of voluntary organisations. People affected by cancer, their family and friends can also meet many needs themselves. Health and social care professionals should work together with patients and carers to ensure that their needs are met.

Studies have shown that patients do not always feel that they are well informed about the details of their disease or treatment. They can also feel left in the dark about what is happening in their treatment and care, especially when moving from the care of their GP to that of hospital doctors and back again. And many feel alone and lacking support, with little ability to affect what happens to them.

Supportive and Palliative Care Guidance has been prepared to advise those who develop and deliver cancer services about what is needed to ensure that patients and their families feel well informed, cared for and supported. Produced by the National Institute for Clinical Excellence (NICE), it complements other Guidance on the treatment of individual cancers.

This is a very shortened version of the Supportive and Palliative Care Guidance, intended both for people affected by cancer and for the wider public. It was developed in close consultation with people living with cancer as well as health and social care professionals. The full version is available on the NICE website ([www.nice.org.uk](http://www.nice.org.uk)) or can be obtained from [*to be added*].

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### **What do people whose lives are affected by cancer want and need?**

Studies show that patients with cancer want to be treated as individuals and to be given dignity and respect. They want access to the best treatments and to be able to exercise real choice about their treatment and care. Most patients want to receive detailed information about their condition and possible treatments in an honest, timely and sensitive manner. Where needed, they expect to be offered emotional, social and spiritual support. They want to be able to die in the place of their choice, often their own home, with good control of pain or any other distressing symptoms. Finally, they want to be assured that their family and other carers will receive help and support both during their illness and following bereavement.

The Guidance recommendations have been developed to meet these expectations, outlining a service centred on the needs of the individual. 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 patient care encompasses a broad range of needs, from the initial diagnosis through to terminal care
- valuing the knowledge, skills and resources which patients and their families already have, enabling them to contribute to their own care and support
- involving patients in the planning of services
- ensuring that services are ethnically and culturally appropriate and accessible to people with physical and sensory disabilities

The NHS is working with patients and carers to put all the Guidance recommendations into practice.

### **Key Recommendations**

**People affected by cancer and their carers should be involved in developing NHS cancer services.**

People who use cancer services can make an important contribution to the development and delivery of services because they know from first hand experience what is needed. They should be involved in developing supportive and palliative care services, by advising or becoming members of local NHS planning groups. They should also be involved in looking at whether such services meet patients' and carers' needs, so that changes can be made where necessary. Training and support should be offered to enable people to participate effectively.

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**People affected by cancer should be involved in decisions about their care, following honest and sensitive discussions with professionals, and should find that staff have kept each other informed.**

Learning that you have cancer has a profound impact both on a patient and on their family and other carers. Wherever possible, this information should be given by a senior health professional, 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. All staff working with patients should have some training in sensitive and honest communication, as well as in supporting patients' choices. All significant discussions should be recorded in a patient's notes and the patient should be offered a record of key points.

A frequent concern of patients is a lack of co-ordination between the many doctors, nurses and others working with them, 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. It is important that all those involved in their care inform each other about developments affecting individual patients, so that there is good continuity, and then work together to respond to agreed needs. Patients and carers can also feel unsure about who to contact and how to obtain the help that they need. There should therefore be a 'key worker' who they can contact and who is familiar with the planned treatment and care.

**People affected by cancer should be able to obtain free information about cancer and cancer services.**

People with cancer cannot be fully involved in decisions about their treatment and care if they are not well informed. At present, many patients report that they receive inadequate information. Most patients want to learn about the nature and course of their particular cancer, potential treatments including pain and symptom control, and the full range of support available to them, including self-help organisations. Some also want information on complementary therapies.

Patients and carers should have easy access to a range of information about cancer and cancer services, offered routinely both at initial diagnosis and at other significant points. Staff should provide information materials and offer to discuss these 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 emotional, spiritual and social support to meet their individual needs as well as help with symptom management.**

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 has an impact on the whole

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of a person's life, including family relationships and wider social networks, employment and finances, and the ability to meet personal care needs. Although many people are able to meet these needs themselves, there may be times when they need additional help from another source.

All professionals should be alert to the needs of patients and their families for practical help, for instance on employment issues or state benefits, assistance with personal care, or cleaning or shopping. They should also be aware of potential needs for spiritual or emotional support. Patients and carers should regularly be asked about their needs at key stages, including on diagnosis, at the 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 offer such help, whether people are living in their own home, a care home, a hospice or staying in hospital.

People can also get great benefit from talking to others in the same situation. Many gain reassurance from meeting someone who has been through their proposed treatment and who understands their anxieties. 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. 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 needs of family and other carers of people with cancer should be recognised and met.**

Cancer does not only affect the patient. It can also have a devastating impact for the whole family and close friends. They are often the people who provide essential day-to-day support and practical assistance. Their own needs for emotional and practical support, however, often go unrecognised. There can be a tendency for family members and other carers to put the needs of the patient first, so they should be explicitly asked about their own needs, particularly at crucial times such as diagnosis, recurrence or death. In every local area, there should be organisational arrangements for developing and delivering services for families and other carers.

### **People living with the after effects of cancer should have access to services to help them to manage these for themselves.**

People are living increasingly longer following 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 kind of difficulties. They are provided by a range of professionals within the NHS, such as physiotherapists and dieticians, and by relevant voluntary organisations.

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Some patients do not obtain these services, either because their needs are not recognised or because of a lack of suitable local services. All areas should ensure that there are comprehensive services of this kind. Local professionals should be alert to the needs of patients and their families for such help and should routinely ask about their needs.

### **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. Medical and nursing services need to be available on a 24 hour basis, seven days a week. Equipment should be provided without delay.

Although this support is normally provided by a GP or district nurse, some people will have particular difficulties which require specialist services, for example for the control of pain. There should be a range of specialist palliative care services in all areas, suitable to meet the needs of local people. Through their local community services, patients and their families should be able to obtain specialist advice 24 hours a day.

### **People should be able to die in the place of their choice and support should be provided to family and other carers.**

People who are dying from cancer and their families have particular needs. These should be identified and addressed by those providing their care, whether it be in the patient's own home, hospital, care home or hospice. People should also be enabled to die in the place of their choice.

Following a death, family members and other carers may need support in their bereavement. Local staff should be alert to such needs and make provision to respond to them.

### **There should be the enough trained doctors and other staff in every area to provide the needed services.**

Many of the recommendations are dependent on having sufficient health and social care professionals in every local area. These need to be properly trained both in their specialist fields and in working closely with patients. Training in recognising the needs of patients and their family, talking with them in an honest manner, listening to their concerns and giving them information and support is particularly important.

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### **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 ([www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) or phone 0845 4647).