

When bowel cancer has been diagnosed at an advanced stage, or if it becomes advanced despite previous treatment, it is more difficult to cure. Your multidisciplinary team will review your scans and tissue sampling (histology) and discuss treatment options. If a cure does not seem to be a realistic goal, then you may be offered palliative care. This means that your doctors and nurses will support you to have the best possible quality of life, rather than trying to cure you. You can still have treatments such as chemotherapy or radiotherapy, which aim to manage your symptoms and may extend your life, and you can continue to expect the best care available for you and your family.

To be told that treatment will be palliative can be very distressing for patients, and they wonder if it means they will be sent away to die. However, palliative care should ideally be put in place early in a patient's treatment plan. This care has been shown to be very effective in helping people to live more comfortably for longer, and to maintain their dignity and independence as well as having positive effects on their quality of life. Palliative care is a treatment in itself.

Palliative care is designed to:

- react quickly to your changing health and social care needs
- recognise the importance of dignity and respect, and pay attention to your emotional and psychological needs
- treat your pain or other distressing symptoms quickly and effectively
- make the most of life and treat dying as part of a normal, natural process
- offer support and information that meets your needs and the needs of your family.

Palliative care is a team approach, with support and care provided by NHS workers such as your GP, specialist palliative care team and community nurses, as well as social services and a range of voluntary organisations.

Referral to palliative care services is made either by your specialist nurse at the hospital or your GP and should be put in place early in your treatment plan. This can take place alongside treatments such as chemotherapy and radiotherapy, which are used to help

prolong your life and keep your cancer under control for as long as possible.

Having some contact with a palliative care team means you will be able to share concerns or changing needs with them and have problems dealt with more promptly.

Supporting carers and family

Bowel cancer does not only affect the patient; it can have a devastating impact on your family and close friends too. They may find themselves in a carer's role, which is something that they had not expected and are not prepared for. The role of caring can be time-consuming, and at times can also be physically and emotionally draining.

It might be that having a chat with a friend or their GP is enough to let off steam, and carry on refreshed. Beating Bowel Cancer has an online forum and a Facebook carers' group which can be good sources of support.

Carers and family members are usually able to use cancer services attached to your local hospital, a hospice, or a centre such as Maggie's, for counselling or other therapies.

It can be hard to know how to support children and teenagers. However, it is always best to be open and honest with children, which allows the family to support each other. We've included some useful links at the end of this factsheet.

It is important to ask for help if the situation is becoming difficult to cope with. If you are providing regular and substantial care for someone, ask to be assessed by your local authority (council) so that it can agree what support you need. The best way to request a carer's assessment is to contact the social services department at your local authority.

The assessment will consider the sort of caring you do, how much time you spend doing this, and how much support you already receive. It will also take into account whether you live with the patient or not, whether you care for others, and your own health and well-being.



Beating Bowel Cancer

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It is important to be honest and open about how much help you need, and what kind of support might be most useful to you, for example:

- equipment or modifications in the home
- someone to help with personal care
- having a hot meal delivered for the patient
- having a regular break for yourself
- counselling or just someone to talk to
- being put in touch with other carers.

Hospices

Hospices care for people with a life-shortening illness, but going to a hospice does not mean that you are about to die. Some people are referred to a hospice as soon as they are diagnosed and may visit a hospice several times over many years for care or respite. You can also attend as a day visitor if you prefer.

Hospices provide skilled, compassionate care for people of all ages, and their families. They create a calm, comfortable and relaxing environment and offer care that is tailored to your personal needs and wishes. They are often situated in lovely grounds with tranquil gardens.

You can also take part in creative activities, such as art classes, or enjoy complementary therapies such as massage or reflexology. Most hospices have accommodation for relatives and may provide a TV and/or wi-fi. They can support your family and carers, helping to take the pressure off them. Hospices provide spiritual care, for those who might welcome this.

Hospice care is always free. Some hospices are funded by the NHS and others by charities, but there's never a charge.

It is very likely that you will be allocated a community palliative care clinical nurse specialist as a source of ongoing support. They are also a link back into inpatient services if and when you need them.

Planning ahead

If you are diagnosed with non-curative bowel cancer, any plans in place suddenly look very uncertain, as you find yourself facing a host of practical, financial and emotional difficulties. You may want to make important decisions about care and treatment in the later stages of your illness. Starting to work through these issues while you are well, and putting plans in place for the future, may help give you some peace of mind. It can be helpful to talk to your healthcare

professionals about your wishes. If you prefer, your family can be included in these conversations.

These choices about care can be documented by your team and kept safely with your medical records. The paperwork is known by several names: advance decision, advance directive or a living will. Currently in England and Wales, medical staff use a form called Preferred Priorities of Care to keep a record of your wishes. Your wishes can be reviewed regularly, and communicated to the key people involved in your care. The form may have a different name in Scotland and Northern Ireland.

Further information and support

Beating Bowel Cancer

Support by phone and email from our nurse advisors, a patient to patient support network, a patient and relative online forum, plus a Facebook carers' page and Facebook support groups.

T: 020 8973 0011

BUPA

Information booklets about cancer for children aged 7 – 11

W: www.bupa.co.uk/iknowsosomeonewithcancer

Carers UK

Practical and emotional support for carers

T: 0808 808 7777

W: www.carersuk.org

Help the Hospices

Information and support about hospices

T: 020 7520 8200

W: www.hospiceuk.org

Macmillan Cancer Support

T: 0800 808 0000

W: www.macmillan.org.uk

Maggies Centres

Support for cancer patients and their families

W: www.maggiescentres.org

Rip Rap

For teenage children of cancer patients

W: www.riprap.org.uk

Winston's Wish

Guidance for parents on the amount of information to give to children, plus a list of books suitable for younger children.

W: www.winstonswish.org.uk



If you have any questions or comments about this publication, or would like information on the evidence used to produce it, please write to us or email info@beatingbowelcancer.org.

