

# Advanced Colorectal Cancer

An information guide



# Advanced Colorectal Cancer

Advanced bowel cancer is cancer that has spread from the colon or rectum to other parts of the body such as the liver, lungs, lymph nodes or lining of the abdomen (peritoneum).

Your cancer may have been at an advanced stage when you were first diagnosed or it may have come back and spread after treatment for the original cancer.

Although it is rare for advanced cancer to be cured, treatment such as chemotherapy, radiotherapy, colonic stent or surgery can still be given to control cancer and improve the symptoms. This is known as Palliative Care

The definition of Palliative Care is:

*"An approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness."*

The treatment you are offered will depend on:

- Where the cancer is in your body.
- The symptoms you are experiencing.
- How you have responded to other treatments.
- Your overall health and fitness.

It is natural to feel frightened bewildered and shocked when you are told you have advanced bowel cancer. You will be given a lot of information, which may feel overwhelming at first, but you do not have to make any decisions about treatment straight away.

Before you make a decision, a consultation will take place with you, family members and your medical team.

## Questions you may want to ask at your appointment:

- What are my treatment options?
- If I have treatment how much longer am I likely to live?
- What happens if I do not have treatment?
- What are the likely side effects?
- What emotional, financial or family support is available?

Following your consultation you may decide not to have any treatment or your medical team may not think you are suitable. If chemotherapy or radiotherapy is an option, you can have this until it no longer controls the cancer or you start to get side effects from it.

At this point or at any time you need help to ease symptoms of cancer your GP or Colorectal Nurse can refer you to the palliative care team in your area.

## What support is available?

**Specialist Palliative Care Nurses** are expert in medications to help you manage symptoms such as pain, nausea and digestive problems. They can also help you plan for the future and provide emotional support.

**Occupational therapists** can provide equipment such as safety rails shower seats or kitchen aids to help keep you independent. They can also help manage low mood and fatigue by changing your routines and activities.

**Physiotherapists** can offer exercise programmes to keep you moving and relieve pain.

## **Cancer support centres and community cancer support**

Cancer support centres offer a range of support and information including: practical support for patients, family and friends, exercise and nutrition advice, relaxation and stress management, counselling and emotional support and help claiming benefits.

**Macmillan Information and Support Service (Northern Care Alliance)** – The Macmillan Information and Support Service support patients from Bury, Oldham, Heywood, Middleton and Rochdale. They can provide information and support on the practical, emotional and financial effects of cancer. Contact them on **0161 604 5244** or email **macmillan.infocentre@pat.nhs.uk**

**Maggie's (based at The Royal Oldham Hospital)** – You do not need an appointment. Email **Oldham@maggiescentres.org** or call **0161 989 0550**. You can also drop in to the centre. They are open Monday to Friday, 9am to 5pm. During current pandemic restrictions, making an appointment is preferred if you would like to go into the centre in person.

**Maggie's Manchester (based at The Christie Hospital, Manchester)** – You do not need an appointment. Email **Manchester@maggiescentres.org** or call **0161 641 4848**. They are open Monday to Friday, 9am to 5pm. During current pandemic restrictions, making an appointment is preferred if you would like to go into the centre in person.

**Bury Cancer Support Centre (406 Bolton Road, Bury BL8 2DA)** – Bury Cancer Support is open Monday to Wednesday 10:30am to 4pm, Thursday - 3pm to 8pm. Drop in or call **0161 764 6609**. Please note, Bury Cancer Support is operating reduced services during the pandemic. Please do not attend the centre without phoning in advance.

## **Holistic Needs assessment (HNA)**

A HNA gives you the chance to think about your concerns and the help you might need. This assessment will be offered to you shortly after your first hospital appointment. Once you have completed the assessment a colorectal support worker will discuss your concerns and devise a care plan with possible solutions, information and support.

## **Managing symptoms and side effects**

Problems with eating, weight loss, fatigue, bowel changes, pain, nausea and vomiting are common when you have advanced cancer either from the cancer itself or from the side effects of treatment. There are simple things you can try yourself.

Please ask your Colorectal Clinical Nurse Specialist (CNS), your Specialist Palliative Care Nurse, or any professionals looking after you if you are on treatment (such as your chemotherapy nurse) for advice. Macmillan also have some helpful books on managing symptoms and side effects.

## **Fatigue**

Extreme tiredness (fatigue) can be exhausting. You may have difficulty sleeping, concentrating or remembering things. Fatigue can leave you feeling low in mood and more emotional. Fatigue can also be caused by other things such as anxiety anaemia and pain.

- Keep active. Too much rest and sleep in the day does not usually help. Being inactive causes muscle weakness and low mood and makes fatigue worse.
- Keep to a normal sleep pattern.
- Try complementary therapies such as relaxation and yoga.
- Eat well to give you more energy and strength.

## Changes in bowel habit

Bowel cancer can affect how the bowel works.

Tips to help diarrhoea:

- Try to drink plenty of fluids to replace the fluids lost with diarrhoea.
- Avoid alcohol and caffeine.
- Eat low fibre foods such as white bread, boiled white rice, pasta, fish, chicken bananas and mashed potato.
- Avoid fatty greasy and spicy foods.
- Avoid bran, wholegrain cereals and bread limit vegetables and fruit and avoid the skins.

If diarrhoea is caused by chemotherapy or radiotherapy diet alone may not help and anti-diarrhoeal medication such as Loperamide (Imodium) may be needed, speak to your GP or colorectal nurse before taking this.

Tips to help with constipation:

- Eat wholegrain/wholewheat/multigrain cereals and bread, fruit and vegetables.
- Drink plenty of fluids including water (eating a lot of fibre without drinking enough can make constipation worse).
- Gentle exercise will keep your bowels moving.

Strong pain relieving medication can cause constipation and laxatives may be needed. Speak to your Specialist Palliative Care Nurse or Colorectal Clinical Nurse Specialist for advice.

## **Nausea (feeling sick)**

- Eat dry foods such as toast or crackers and light foods such as eggs and soup.
- If the smell of cooking makes you feel sick, eat cold food or meals from the freezer.
- Avoid fatty greasy fried food.
- Sit by an open window to allow fresh air in the room.
- Try ginger biscuits, ginger ale, crystallised ginger or ginger tea.
- Slowly sip fizzy drinks through a straw.

Some medications and constipation can also cause nausea. Speak to your Specialist Palliative Care Nurse or Colorectal Clinical Nurse Specialist for further advice.

## **Information booklets on symptoms and side effects**

*(order for free through the Macmillan Information and Support Service)*

- Macmillan 'Managing the side effects of cancer treatment'
- Macmillan 'Eating problems and cancer'
- Macmillan 'Managing cancer pain'
- Macmillan 'Coping with fatigue (tiredness)'

## **Online information on symptoms and side effects**

### **Nausea and vomiting:**

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/nausea-and-vomiting>

### **Tips for managing bowel and bladder changes:**

<https://www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment/radiotherapy/pelvic-radiotherapy/tips-for-coping-with-bladder-or-bowel-changes>

### **Pain:**

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/pain>

### **Changes in weight:**

<https://www.macmillan.org.uk/cancer-information-and-support/treatment/coping-with-treatment/changes-in-weight>

### **Fatigue:**

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/tiredness>



## **Financial Help**

Cancer can cause financial difficulties such as added expense from travelling to hospital for treatment, car parking charges and increased heating bills.

Your income may also have been affected if you can no longer work or work part time. You may be eligible to apply for financial assistance and if someone is caring for you they may also be entitled to benefits.

Macmillan Benefits Advisors can provide advice and support on what you may be entitled to, including Macmillan Grants (one off means tested grants of £350 for people with a cancer diagnosis). They can also help you with filling in any forms.

If you would like a referral to a Macmillan benefits advisor, please get in touch with the Macmillan Information and Support Service on **0161 604 5244** or email **macmillan.infocentre@pat.nhs.uk**.

You can also access Benefits Advisors through the Maggie's Centre's by calling **0161 989 0550** or emailing **Oldham@maggiescentres.org**.

The National Macmillan helpline can also provide general advice on anything related to money and cancer **0808 808 00 00**.

### **Information booklets on money and cancer**

Macmillan 'Help with the cost of cancer'

Macmillan 'Money worries: how we can help'

### **Online information on the financial impact of cancer**

#### **Financial Guidance:**

<https://www.macmillan.org.uk/cancer-information-and-support/get-help/financial-help/financial-guidance-help-line>

## **Emotional support**

It is natural to feel overwhelmed by feelings of sadness, fear anxiety or anger when you are first told about your diagnosis.

If you are finding it difficult to talk to your family and friends and would like more support to help you cope with your feelings you can be referred for counselling or psychological therapies. You may like to join a support group or on line community where you can share your experience with other cancer patients.

Carers and family members may also be finding it difficult to talk about how they are feeling and may like to join a carers group. There are resources for children or grandchildren who are finding things difficult to cope with.

All the Cancer Support Centres listed on page 4 can be contacted for emotional support.

## **Counselling service at Beechwood Cancer Centre**

Beechwood Cancer Centre is based in Stockport and provide specialist counselling to people with a cancer diagnosis and their families.

This includes specialist counselling for children of all ages and young people. They are currently offering telephone counselling.

You can self-refer to Beechwood for counselling by calling them on **0161 476 0384** or emailing

**[enquiries@beechwoodcancercare.co.uk](mailto:enquiries@beechwoodcancercare.co.uk)**.

Alternatively, you can call the Macmillan Information and Support service (contact details on page 4 of this leaflet) to request to be referred by a professional.

## **Writing a will and thinking about future priorities**

Writing a will is often something people think about when they receive a life changing or life limiting diagnosis. It gives people peace of mind and makes sure that your wishes are followed through once you die.

You may find that writing a will or updating an existing will makes you feel less anxious about the future. Both Macmillan and Cancer Research UK offer a free will writing service through local solicitors who are part of their schemes. You can call them to find out more information and to find out how to use their services.

If you do not want to use their services, you can get quotes from other solicitors. To find a list of solicitors near you, you can look on the Law Society website [lawsociety.org.uk](http://lawsociety.org.uk) or call **020 7242 1222**.

## **Information booklets on will writing and future priorities**

Macmillan 'Sorting out your financial affairs'

Macmillan 'Your step-by-step guide to making a will'

## **Online information on writing a will**

### **Writing a will:**

<https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/writing-a-will>

### **Sorting out practical and financial affairs:**

<https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/end-of-life/sorting-out-practical-and-financial-affairs>

## **Talking to children**

Talking to children about cancer is extremely difficult. It is natural to want to protect them from painful experiences. You will know the best way to talk to the children in your family but you may want to think about the different ways this can be approached.

It is important to be honest and use age appropriate language. It is helpful to talk to the school, nursery or college that the child attends as they can be a great resource in supporting your child.

You might also want to access support through GPs, social workers or ask for specialist counselling (such as Beechwood mentioned on page 10) if you feel a child needs it.

## **Information booklets on talking to children**

Macmillan 'Talking to children and teenagers when an adult has cancer'

Macmillan 'Preparing a child for loss'

## **Online information on talking to children**

### **Talking to children and teenagers about cancer:**

<https://www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/talking-to-children-and-teenagers>

### **Preparing a child for loss:**

<https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/end-of-life/preparing-a-child-for-loss>

### **Answering questions:**

<https://www.mariecurie.org.uk/help/support/diagnosed/talking-children/questions-children-may-ask-when-someones-ill>

## **Other helpful resources**

### **Macmillan Oldham 1-1 Service**

Macmillan Oldham 1-1 is a community service that provides a range of holistic support to people who live in Oldham or have a GP in Oldham.

The team can offer emotional and psychological support as well as practical advice and guidance on symptom management.

They can be contacted on **0161 621 7684**. You can self-refer or ask to be referred by a professional who is looking after you.

**Notes:**



**If English is not your first language and you need help, please contact the Interpretation and Translation Service**

Jeśli angielski nie jest twoim pierwszym językiem i potrzebujesz pomocy, skontaktuj się z działem tłumaczeń ustnych i pisemnych

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**For general enquiries please contact the Patient Advice and Liaison Service (PALS) on 0161 604 5897**

**For enquiries regarding clinic appointments, clinical care and treatment please contact 0161 624 0420 and the Switchboard Operator will put you through to the correct department / service**

The Northern Care Alliance NHS Group (NCA) is one of the largest NHS organisations in the country, employing 17,000 staff and providing a range of hospital and community healthcare services to around 1 million people across Salford, Oldham, Bury, Rochdale and surrounding areas. Our Care Organisations are responsible for providing our services, delivering safe, high quality and reliable care to the local communities they serve.

The NCA brings together Salford Royal NHS Foundation Trust and the hospitals and community services of The Royal Oldham Hospital, Fairfield General Hospital in Bury, and Rochdale Infirmary (currently part of The Pennine Acute Hospitals NHS Trust).

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**Date of publication: April 2021**

**Date of review: April 2021**

**Date of next review: April 2023**

**Ref: PI(SU)1102**

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