

Colorectal Cancer and Living Well

Workshop Handbook and Self Supported Follow-up



This information is available in audio, Braille, large print and other languages. To request a copy, please ask a member of staff.

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Contact details for your Clinical Team

Colorectal Nursing Team: Heather Baggaley CNS **Tel: 01270 612047** Nicola Thibeault CNS

Sarah Taylor CNS

Stoma Care Nurse Team: Julie Woodcock

Tel: 01270 612443 Charlotte Backhouse

Sylvia Hanson Kyle Waring

Colorectal Cancer Support Workers: Esther Morgan **Tel: 01270 612047** Kerry Wilson

Contact during normal office hours. If you need to leave a message the clinical team will respond within one working day.

Purpose of the workshop

We would invite you to chat with the person next to you (for 3 minutes max) about your response to the question below:

What were your thoughts about coming to the workshop today?

Purpose

- 1. To make sure you have got everything you need to feel confident about your Supported Self-Management and Remote Follow Up patient pathway.
- 2. To give you the skills and confidence to check your symptoms and to look for any signs of cancer recurrence.
- 3. To manage lifestyle changes and to set your own goals for recovery and rehabilitation.

How can we all make this session work in the best possible way?

- 1. All of you can add your experiences and ideas so you can help each other.
- 2. Opinions are allowed. You don't all have to agree and we expect differences of opinion.
- 3. Try to go along with all of the activities as best you can. There's always a good reason for these.
- 4. Give space for everyone in the group to speak.
- 5. Respect other people's privacy (you may want to talk about this workshop with your family and friends, which is great, but we'd ask that you don't give any personal details of the people in your group).
- 6. We can offer our team's clinical expertise and get answers to any questions we don't have immediate answers to.
- 7. Please feel free to leave the group for comfort breaks.

Workshop Aims

- 1. To develop an understanding that self-management means you work with and are supported by your healthcare team
- 2. To provide help with monitoring symptoms, tracking test results and contacting your clinical team when you need to.
- 3. To increase understanding and awareness of both the physical and the emotional impact of bowel cancer and how best to manage this.
- 4. To help you return as best you can, to a lifestyle as you used to know it.
- 5. To direct you to relevant information and support so that you can live as full and as active lifestyle as possible.

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How will I be informed of my test results?

Blood Test

You will receive a letter informing you that your CEA (tumour marker) blood test is due. The blood request will be made electronically and will be printed at the phlebotomy clinic, here at Leighton when you attend for your test. If for any reason your blood test is abnormal, you will be contacted by a member of your Colorectal Support Team.

CT Scan - Chest, Abdomen and Pelvis

You will receive a letter informing you that your surveillance CT scan is due. You will need to attend for a blood test to check your kidney function. This is standard practice prior to a CT scan. The blood request will be made electronically and will be printed at the phlebotomy clinic here at Leighton when you attend for your test. You will not be able to have your scan done if you do not have this blood test performed.

Once you have attended for your blood test you will be assigned an appointment date for your CT scan and will be notified in a letter directly from the X-ray Department.

Colonoscopy

You may need a colonoscopy at some stage during your follow up period but your Colorectal Support Team will advise you how often they should be performed.

Health MOT

This will be performed at regular intervals during your follow up. Your Health MOT is a questionnaire about your general health and bowel function. Your Colorectal Support Team will have discussed this with you at the Workshop and will contact you by telephone to complete the questionnaire. Please highlight any concerns you may have to your Colorectal Support Team who will be able to provide further information and support if necessary.

Health MOT Checklist

We will complete your Health Checklist together with you over the telephone every time you have an investigation performed such as a blood test or scan, or whenever you have a new concern. This provides us with information to give you the best support to manage your condition.

Practical Concerns Distress Level	☐ Caring responsibilities	☐ Washing and dressing ☐ Transport or parking	☐ Travel☐ Work or education
	☐ Preparing meals/drinks	☐ Money or finance	☐ Laundry or housework
	☐ Grocery shopping	☐ Taking care of others	☐ Housing
	☐ Talking or being understood	□ Pets	☐ Problems with alcohol
	☐ Smoking Cessation	☐ Difficulty making plans	or drugs
	☐ My medication		
Family/	☐ Children	☐ Partner	☐ Other relative or friend
Relationship Concerns Distress Level	☐ Person who looks after me	☐ Person who I look after	
			,
Emotional	☐ Anger or frustration	☐ Guilt	☐ Loneliness or isolation
Concerns Distress Level	☐ Worry, fear or anxiety	☐ Loss of interest/ activities	☐ Hopelessness
	☐ Unable to express feelings	☐ Sadness or depression	☐ Uncertainty
	☐ Independence	☐ Thinking about the future	☐ Regret about the past
Spiritual Concerns Distress Level	□ Faith or spirituality	☐ Not being at peace or feeling regret about the past	☐ Meaning or purpose of life
			,
Physical Concerns	☐ My appearance	☐ Breathing difficulties	☐ Passing urine
Distress Level	☐ Constipation	☐ Diarrhoea	☐ Eating, appetite or taste
_	☐ Tired/exhausted or fatigued	☐ Swelling	☐ High temperature or
	☐ Hot flushes/sweating	☐ Moving around (walking)	fever
	□ Mamaria.		☐ Indigestion
	☐ Memory or concentration	☐ Sore or dry mouth or ulcers	☐ Nausea or vomiting

Physical Concerns	☐ Pain or discomfort	☐ Sex/intimacy/fertility	☐ Dry, itchy or sore skin
Distress Level continue	☐ Sleep problems ☐ Wound care	☐ Speech or voice problems	☐ Tingling in hands/ feet
	☐ Swallowing	☐ Change in weight	☐ Sight or hearing
		□ Cough	☐ Other medical
			conditions
Information or Support Distress Level	☐ Complementary Therapies	☐ Diet and nutrition	☐ Exercise and activity
Distress Lever	☐ Sun Protection	☐ Making a will or legal advice	☐ Planning for my future priorities
	☐ Managing my symptoms	☐ Patient or carer's support groups	☐ Health and wellbeing
Other Concerns			
Additional Comments			

Follow up tests explained

CEA Testing

This is a blood test that measures the amount of Carcinoembryonic Antigen (CEA) in your blood. CEA is a marker made by some types of cancer, including bowel cancer.

Following a diagnosis or treatment for bowel cancer the CEA can be good way of monitoring your condition. You may have to have regular tests as advised by your Colorectal Support Team. Please refer to page 6 for information on how you will receive notification of this test.

The expected level of CEA varies with each different type of treatment of bowel cancer and your Colorectal Support Team will be able to guide you as to what is considered normal for you following treatment.

CT Scan - Chest, Abdomen and Pelvis

You may also have regular CT scans of your chest, abdomen and pelvis. This will be performed as outlined by your Colorectal Support Team. This is to check for any recurrence or secondary spread from your original cancer. Prior to this scan you will be required to have a blood test. This is to check that your kidneys are working satisfactorily. The scan cannot be performed without this blood test. Please refer to page 6 for information on how you will receive notification of this test. You will be sent a second letter informing you of the results from your Colorectal Support Team. A letter with your scan results will also be sent to you GP.

Important signs and symptoms

It is important to report to the clinical team any of the symptoms listed below. These symptoms **do not** necessarily mean the bowel cancer is more active or has returned. They may be due to side effects of treatment or completely unrelated to your condition. By contacting your clinical team by phone, they will be able to advise and reassure you. If necessary they can arrange any investigations that might be required.

- Blood and mucus from your back passage or mixed with your motion: Most commonly this can be related to haemorrhoids (piles) or straining if constipated. Sometimes it is due to a tear around your back passage (anal fissure). Occasionally this could be due to an unrelated bowel disorder or may indicate a bowel cancer so this needs to be reported and investigated promptly.
- Pain in your back passage/ pain on opening your bowels: This could indicate a tear in your back passage (anal fissure), but may require further investigation.
- Change in bowel habit: Either to looser more frequent motions with increased wind from
 your back passage, or alternatively if you become constipated and are struggling to go. This
 could be the consequences of surgery or a dietary problem or the fact you are taking
 painkillers which could make you constipated. It also could indicate an unrelated bowel
 condition or a bowel cancer so this needs to be reported and investigated promptly.

- Feeling of pressure or wanting to have your bowels open all the time: This could be
 the fact that you have haemorrhoids (piles) in your back passage, or that you are
 constipated. However this could indicate a polyp or cancer present so this needs to be
 reported and investigated promptly.
- **New or worsening incontinence:** This could be a symptom from your surgery or as a result of weak muscles in your back passage. You may find that you have to start wearing a pad. Please report this to your Colorectal Support Team.
- Pain in your abdomen, bloating or a change in tummy size: This could be an unrelated bowel disorder or may indicate a bowel cancer so this needs to be reported and investigated promptly.
- **Unplanned weight loss:** This could be due to stress, worry or related to dietary intake. However this should be investigated.
- **Problems or difficulty regarding intimacy:** Contact your Colorectal Nurse or GP who will be able to refer you to a Specialist if required.

If you are concerned about any of the above, please contact your Colorectal Support Team for advice or reassurance.

Emotional Impact: Is the bowel cancer going to come back or will it get worse?

After treatment, some people will put their cancer experience to the back of their mind and hardly ever think about it. Uncertainties may not bother them. Others think about cancer often and find that those thoughts are overwhelming. They may live with fears about whether their cancer will come back, get worse, or how it will affect their future. Some people will focus on the positive changes cancer has brought, such a new purpose and strength in life. They may more easily accept and adapt to changes and challenges. Any one of these reactions is normal. Some degree or worry is quite normal. It would be uncommon not to be worried about these issues at some point.

When to ask for help

- You are finding it difficult to rebuild your life because of uncertainty about bowel cancer.
- You constantly worry that the bowel cancer is going to come back or is going to spread / get worse.
- You worry about bowel cancer before you go to bed at night and first thing in the morning.
- You are having problems sleeping that have lasted for a few weeks or more.
- You have little or no appetite.
- You have no desire to spend time with friends.
- You have little or no interest on carrying on with your normal routines.
- You are finding it difficult to concentrate.

Emotional Impact: Ways to manage worry and uncertainty about bowel cancer.

- Learn to focus on the ways bowel cancer has made you a stronger person
- Talk to family and friends about your concerns.
- Join a support group, details of which can be provided by your Colorectal Support Team.
- Write a diary about your fears and feelings.
- Get involved with an interesting hobby or others things you enjoy doing.
- Review your priorities and direct your time towards interesting and meaningful activities.
- Remember that as time goes by, these worries will fade.
- If depression, anxiety or any part of the cancer journey becomes overwhelming seek advice from Colorectal Nurse Specialist or GP.

Some friends and family members may be uncomfortable talking about cancer. If that is the case, it is very important to remind yourself:

- You have done nothing wrong by bringing the subject up the other person may be responding to his or her own experience and fear of cancer.
- The other person may not know how to discuss the subject.
- Although what they said may not be what you wanted to hear, it may be that this person is doing the best he or she can right now.

Find a Cancer Support Group

Support groups can provide a safe environment to share experiences with other people who have gone through similar experiences. You can also learn new ways to handle difficult situations and talk about emotional issues that only other people like you will understand. These groups can offer an opportunity to learn different ways of coping. Macmillan Cancer Support are examples that can help. Your Clinical Nurse Specialist and Colorectal Support Team can signpost you to local support groups in your area.

Talk with a professional therapist if worry or low mood overwhelms you

Counsellors are trained to listen and can help you to find your own ways to deal with things. Your Colorectal Nurse Specialist and Colorectal Support Team will be able to refer you to a psychologist who specialises in cancer care. Your GP could refer you to a counsellor or you can pay for one and arrange yourself.

Healthy Lifestyle: Top tips for a healthy bowel

Fibre

Foods high in fibre are a great choice for a healthy bowel. Eating a good amount (about 25-30 grams daily) of high fibre foods are such as raspberries, bananas, prunes, peas, broccoli, beans and whole wheat pasta are a great way to cleanse your bowel. Other fibre high wholegrain foods include brown rice, whole wheat breakfast cereals such as Weetabix, Shredded Wheat, Special K or muesli. Smoothies are also a good way to increase your daily intake of fibre. These can be obtained at your local supermarket. Fibre keeps bodily waste moving along your digestive tract ensuring healthy bowel movements.

Water

Not enough water can lead to a build-up of toxins in the body. This can increase your likelihood of constipation, fatigue, bloating and wind. For a healthy bowel try to drink at least eight glasses of water spread over the day. You can always add fruit cordial to your water if you prefer.

Exercise

Exercise contributes a high part in maintaining a healthy bowel. Research has demonstrated that it can even prevent cancers! Exercise increases blood flow and oxygen to the blood supply in your gut. Your exercise regime does not need to be extreme. Stretching, pilates, yoga, swimming or walking for 20 minutes a day is sufficient to keep your bowel healthy.

Painkillers

If you take regular painkillers and you are prone to constipation, it is advisable to take a regular small dose of laxatives. Your Colorectal Nurse or GP can advise.

Eat less red and processed meat

A diet high in red and processed meat is known to contribute towards the development of bowel cancer. Try to limit to once a week and try eating more chicken and fish.

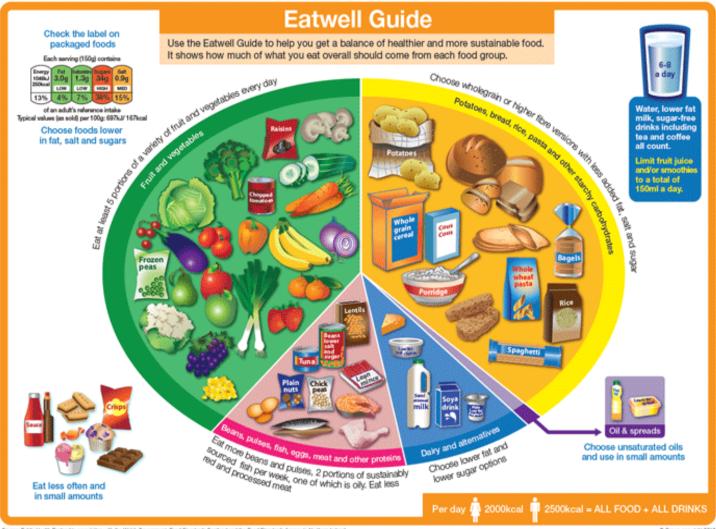
Tip: Do not hold on to it!

If you have the sensation to have your bowels open, head for the toilet!

If you try to hold on and put it off it can lead to straining, bloating and constipation.

Healthy Lifestyle: Healthy eating

- Eat plenty of fruit and vegetables
- > Starchy foods should make up about one third of the food you eat. This includes bread, rice, potatoes, pasta and other starchy foods. Choose wholegrain varieties whenever you can because they can be a good source of fibre.
- Include some milk and dairy foods.
- Also include meat, fish, eggs, beans and other non-dairy sources of protein
- > Try and reduce your weekly input of red meat (pork, lamb and beef). Also cut down on processed meat, these include bacon, ham, salami, sausages, spam, corned beef, black pudding, pate and tinned meats. Eat chicken and oily fish instead.



Source: Public Health England in association with the Weigh Government, Food Standards Scotland and the Food Standards Agency in Northern Instand

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Healthy Lifestyle: Top tips for a healthy weight

Keep to your meal routine

Try to eat roughly the same time each day. This will help you avoid snacking and eating more calories.

Go reduced fat

Choose reduced fat versions of food such as dairy products, spreads and some salad dressings. Use them sparingly. Change to semi skimmed milk and save 60 calories each day (based on consuming 300mls of milk a day).

Walk off the weight

Walk 10,000 steps each day. Try using a pedometer to help count the steps. You can break up your walking throughout the say. Take the stairs rather than the lift.

Pack a healthy snack

Choose healthy options such as fresh fruit, a handful of nuts, or low calorie yoghurt. Have a banana instead of a chocolate bar and save around 150 calories. Take a piece of fruit to work. Choose yoghurts with less than 100 calories. Calcium will keep your bones healthy.

Look at labels

Be careful about food claims. Check the fat and sugar content on food labels.

Caution with your portions

Do not heap food on your plate (except vegetables and salad). Cook smaller portions and use a smaller plate.

Think about your drinks

Choose water or sugar free squashes. Unsweetened fruit juice is high in natural sugar so limit to one small glass a day. Alcohol is high in calories so limit the amount you drink.

Focus on your food

Slow down. Do not eat on the go or while watching TV. Eat at the table wherever possible.

Eat at least 5 portions of fruit and vegetables a day whether fresh, tinned or frozen (400g in total). A medium sized apple or banana or three heaped tablespoons of peas is one portion.

Healthy Lifestyle: Top tips to combat cancer related fatigue

Fatigue is being tired – physically, mentally and emotionally. It means having less energy to so the things you need to or want to do. Cancer related fatigue is one of the most common side effects of cancer treatment and often occurs without warning. Every day activities such as talking on the phone, shopping and even eating a meal can be overwhelming. Cancer related fatigue is worse than everyday tiredness. It lasts longer and sleep does not make it better. People have described it as overwhelming, affecting every part of their lives. Cancer related fatigue can last from months to years. It often continues after treatment has finished.

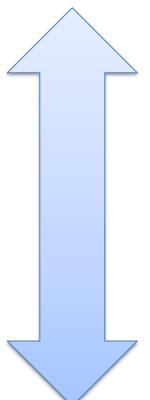
There may be a medical reason as to why you are experiencing fatigue such as anaemia, pain, anxiety, stress or the consequences of cancer treatment. If you are concerned ask for advice from your Colorectal Nurse Specialist, Colorectal Support Team or your GP.

Tips to help with cancer related fatigue.

- Take it easy Set aside time in the day to rest. Take a short nap no longer than an hour.
- Conserve your energy for important activities. Ask for help when needed.
- **Maintain your energy.** Drink lots of fluid and eat a well-balanced diet. Limit caffeine and alcohol and drink plenty of water.
- **Get moving.** When you feel up to it, light exercise throughout the week may help preserve your energy level.

Though fatigue is a common symptom when you have had cancer, there are steps you can take to reduce or cope with your symptoms. Contact your Colorectal Nurse Specialist, Colorectal Support Team or your GP who can advise you on how you can find more information.

Healthy Lifestyle: Benefits of physical activity



Improves low mood or depression Improves your quality of life Improves bone health Improves heart health Builds muscle strength Helps maintain a healthy weight

Reduces cancer-related fatigue Reduces stress and anxiety Reduces the risk of:

- High blood pressure
- Heart disease
- Kidney disease
- Diabetes
- Stroke
- Osteoporosis

Healthy Lifestyle: Top tips for exercising

Exercise and keeping active has shown to be beneficial both during cancer treatment and keeping yourself fit following a cancer diagnosis. It is important to make sure that your physical activity is appropriate for you. If you need advice, contact your Colorectal Nurse Specialist, your local Macmillan Information Centre or your GP who will advise you on our local physical activity programmes in your area, such as walking groups, cycling, swimming, yoga, tai chi and exercise classes at your local gym. As you gradually build up your strength you can choose what activity you enjoy the most.

Being active has many benefits such as:

- Reducing tiredness and fatigue.
- · Reducing anxiety and depression.
- Improving your mood.
- Strengthening your muscles, bones and joints.
- Helping to look after your heart and reduce other health problems such as diabetes, heart disease and stroke.
- Keeps your weight steady.

Tips:

- ✓ **Start slowly.** If you are not used to exercising you may worry about how to get started. Start off slowly by taking a 20-minute walk if you're starting to exercise. You might feel like it's not enough, but it's a good start. Increase your amount a little at a time.
- ✓ **Get the family or friends involved.** Go walking with friends. Share your plans to exercise with people you know are supportive. Celebrate with a little something special every time you manage to exercise.
- ✓ Ask advice from your GP or health team. If you are unsure about any aspect of exercise and your health.
- ✓ **Don't beat yourself up if you don't manage exercise as planned.** Think about why you didn't get round to it and what you could do differently next time to change that.

Relaxation exercises

Relaxation can help to relieve the symptoms of stress and anxiety. It can help to calm down and take a step back from a stressful situation. Although the cause of the anxiety won't disappear, you will probably feel more able to deal with it once you've released the tension in your body and cleared your thoughts.

All relaxation techniques combine breathing more deeply with relaxing the muscles. Don't worry if you find it difficult to relax at first. It's a skill that needs to be learned and it will come with practice.



Relaxed breathing

Practice deep breathing at a regular time and in a quiet place where you won't be disturbed. Loosen or remove any tight clothes you have on, such as shoes or jackets. Make yourself feel completely comfortable.

Sit in a comfy chair which supports your head or lie on the floor or a bed. Place your arms on the chair arms or flat on the floor or bed, a little bit away from the side of your body with the palms up. If you're lying down, stretch out your legs, keeping them hip-width apart or slightly wider. If you're sitting in a chair, don't cross your legs.

Good relaxation always starts with focusing on your breathing. The way to do this is to breathe in and out slowly and in a regular rhythm as this will help you to calm down.

- Fill up the whole of your lungs with air, without forcing. Imaging your filling up a bottle, so that your lungs fill from the bottom.
- Breathe in through your nose and out through your mouth.
- Breathe in slowly and regularly counting from one to five (don't worry if you can't reach five at first).
- Then let the breath escape slowly, counting one to five.
- Keep doing this until you feel calm. Breathe without pausing or holding your breath.

Practise this relaxed breathing for three to five minutes, two to three times a day (or whenever you feel stressed).

Progressive muscle relaxation

This technique takes around 20 minutes. It stretches different muscles in turn and then relaxes them, to release tension from the body and relax your mind.

Find a warm, quiet place with no distraction. Get completely comfortable, either sitting or lying down. Close your eyes and begin by focusing on your breathing, breathing slowly and deeply, as described above.

If you have pain in certain muscles, or if there are muscles that you find it difficult to focus on, spend more time on relaxing other parts.

You may want to play some soothing music to help relaxation. As with all relaxation techniques, deep muscle relaxation you will need a bit of practice before you start feeling the benefits.

For each exercise, hold the stretch for a few seconds, and then relax. Repeat it a couple of times. It is useful to keep to the same order as you work through the muscle groups.

- **Face:** Push the eyebrows together, as though frowning, then release
- Neck: Gently tilt the head forwards, pushing chin down towards chest then slowly lift again.
- **Shoulders**: Pull them up towards the ears (shrug), and then relax them down towards the feet.
- **Chest**: Breathe slowly and deeply into the diaphragm (below your bottom rib) so that you're using the whole of the lungs. Then breathe slowly out, allowing the belly to deflate as all the air is exhaled.
- Arms: Stretch arms away from the body, reach and then relax.
- Legs: Push the toes away from the body, then pull them towards body, then relax.
- Wrists and hands: Stretch the wrist by pulling the hand up towards you, and stretch out the fingers and thumbs then relax.

Spend some time sitting or lying quietly after your relaxation with your eyes closed. When you feel ready, stretch and get up slowly.

National support and information

Macmillan Cancer Support.

Tel: 020 7840 7840 www.macmillan.org.uk/

Citizens Advice self-help website:

www.citizensadvice.org.uk

World Health Organization

http://www.who.int/dietphysicalactivity/pa/en/

NHS Choices

Includes all NHS online services and information, to help you make choices about your health www.nhs.uk

Macmillan Cancer Support

Maintaining a healthy Lifestyle. Dealing with Fatigue. Health and Wellbeing Events.

Tel: 020 7840 7840 www.macmillan.org.uk

Coping with bereavement

www.macmillan.org.uk

Local support and information

Macmillan Cancer Information and Support Service

Leighton Hospital, Macmillan Centre, Crewe, CW1 4QJ

Tel: 01270 273603

Macmillan.Info-Support@mcht.nhs.uk

Cheshire East - Nantwich Citizens Advice Bureau

Nantwich Library, Beam Street, Nantwich, Cheshire, CW5 5LY

Tel: 03444 111 444 (Advice Line) www.citizensadvicece.org.uk

Cheshire East - Crewe Citizens Advice Bureau

Delamere House, Chester Street, Crewe, Cheshire, CW1 2BE

Tel: 03444 111 444 (Advice Line) http://www.citizensadvicece.org.uk/

Cheshire West - Winsford Citizens Advice

Wyvern House, The Drumber, Winsford, Cheshire, CW7 1AH

Tel: 03445766111

www.citizensadvicecw.org.uk

Move More Cancer Exercise Programme

Crewe Lifestyle Centre, Moss Square, Crewe, Cheshire, CW1 2BB

Tel: 01625 383943EBHealthy@everybody.org.uk



