



Your Guide to Supported Self-management



Contents

Your Personal Details	3
What is supported self-management?	4
What happens at my final clinic appointment?	4
Cancer Care Review	5
Getting back to 'normal'	5
Where can I find support?	5
Dealing with Worries	6
Am I cured?	6
Will my cancer come back?	6
I am worried about symptoms – what can I do?	6
Can I get help with financial concerns?	7
What about relationships and sex?	7
When can I return to work?	7
Can I travel abroad?	7
Staying Healthy	8
What diet should I follow?	8
Tips for a healthy diet	8
Exercise advice	9
Can I drink alcohol?	9
Cancer Specific Information	11
My Personal Follow Up Plan	11
My Tests	11
My Results	11
National information	12
Local information	13

Your Personal Details

Name:

Hospital number:

Date of diagnosis:

Diagnosis:

Treatment and dates:

Surgical Consultant:

Consultant Oncologist (if applicable):

Cancer Nurse Specialist:

Cancer Care Coordinator (if applicable):

What is supported self-management?

Supported self-management allows you to manage your own health and wellbeing. You will be supported to develop the knowledge, skills and confidence to have more control of your follow up. It means that you won't have to come into hospital as often but will still be kept safe. You will still have access to support when you need it.

You may still need to have tests as part of your follow up. This is because for a small number of people, their cancer can return. The tests help find any problems early, and the earlier we find a problem, the more we can do to treat it. You will receive appointments for any follow up tests as usual, and the hospital team will let you and your GP know the results of the tests.

There are two ways in which you can self-manage your care and get information:

- Digitally (online via phone/tablet/computer)
- By post

We will continue to keep a close eye on you whilst you are still under our care after treatment.

If you have any symptoms or worries about any part of your cancer, you can telephone a member of your clinical team. If needed, you will be seen by them at the earliest opportunity.

What happens at my final clinic appointment?

When you visit the clinic for the final time you will have a talk with your Cancer Nurse Specialist, and you will decide together if supported self-management is suitable for you.

You will have a Holistic Needs Assessment (HNA) to identify any concerns or support needs you have. These will be written into a care and support plan together with actions to help meet these needs, and you will get a copy of your care and support plan. You will also get a **treatment summary.** This contains information about your diagnosis and treatment including how your follow up care will be organised, including:

- Future tests
- Possible side-effects and what to look out for
- Symptoms you need to tell your clinical team about
- Cancer Nurse Specialist contact details
- Further help and support

A copy of your treatment summary will be sent to your GP.

Cancer Care Review

You should be invited to talk to a member of your GP/primary care team about your cancer within 3 months after your cancer diagnosis. This is called a Cancer Care Review, and you will receive a further appointment 12 months after your diagnosis. Talking about your cancer with your GP / primary care team is a chance to talk about any concerns and be put in contact with other agencies that may be able to help with on-going or new needs.

Getting back to 'normal'

The end of your hospital follow up and treatment can be a difficult time. Although you can feel relieved that your treatment is over, you may also experience a feeling of "what now?" and miss the security of being seen at the hospital on a regular basis. Some patients find it takes longer than expected to recover fully from their treatment. People have different ways of living with and beyond cancer. There is no right or wrong way. Some people prefer not to talk, while others like talking about their experience.

Where can I find support?

There are many local charities who offer care and support. Examples of the support they can provide include:

• Counselling

- Listening services
- Support groups
- Complimentary therapies
- Activity groups

You can find out more about these services from your cancer support team. We have added information at the bottom of this leaflet that you might find helpful.

Dealing with Worries

Am I cured?

Most doctors do not use the term "cured", as it implies they can give a 100% guarantee that your cancer will never return. We can never make this promise to any patient. The treatment you have had has given you the greatest chance of being well in the long-term.

Will my cancer come back?

The risk that your cancer will come back is different for everyone. By having the treatment recommended by your clinical team, you have reduced the risk of having further problems from your cancer as much as possible.

It is normal to feel worried that your cancer may return. This can make you feel uncertain about the future. Some people find it useful to have someone to talk to about these feelings. Please let your cancer support team know if this is how you feel – they can help find support for you.

I am worried about symptoms – what can I do?

Your supported self-management plan is designed to make sure any problems are found early. It is important that you contact your clinical team if you notice any changes that cause you concern. Where needed they will arrange an appointment for you to be seen in clinic within two weeks. If you have not heard back from the team within two weeks contact the Cancer Nurse Specialist or your consultant's secretary. You will find useful information about symptoms to look out for in your treatment summary.

Can I get help with financial concerns?

A cancer diagnosis can have a lasting effect on your income, but you may be able to get help with NHS costs, such as prescriptions and apply for grants or benefits. To find out if you are entitled to any additional help ask your Cancer Nurse Specialist to refer you to Macmillan Cancer Support, Citizen's Advice Bureau (CAB) or your local social services.

What about relationships and sex?

Relationships can be very difficult following a cancer diagnosis, both emotionally and physically. Some people find it hard to talk about sex or relationship problems because they feel embarrassed or self-conscious. You can contact your Cancer Nurse Specialist or your GP who will be able to support you and talk through these issues.

When can I return to work?

If you are going back to work, it will help to meet with your employer, human resources department or occupational health staff first. It can be useful to have someone else there (such as a work colleague or union rep) to take notes. If you are still having some side effects from the cancer treatment, discuss any reasonable changes that can be made to help you get back to work, including a phased return to work.

The Equality Act (2010) covers all types of cancer and protects against unfair treatment, harassment, victimisation, and unfair dismissal. If you think you are being treated unfairly when you are trying to get back to work you can talk to a Disability Employment Advisor. They are based at Job Centres and Job Centre Plus.

Telling friends and work colleagues about your cancer is the best way to overcome any uneasiness they may have about what has happened to you. You can contact your cancer support team for more information.

Can I travel abroad?

Yes. Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients can find it hard to get travel insurance if they have been treated for cancer. Your local Macmillan Information and Support Services and the Macmillan website have a list of insurers specialising in the cover of patients who have had cancer and will be able to offer advice. The British Insurance Brokers Association [BIBA] <u>www.biba.org.uk</u> may also be able to help with travel insurance.

Staying Healthy

What diet should I follow?

You should try to eat a good, balanced diet. A healthy diet is especially important if you have had cancer. If you require further help speak to your hospital team or GP.

The main part of your diet should come from:

- Fruit and vegetables
- Starchy, preferably wholegrain foods such as rice, pasta or potato
- A smaller part of your diet should come from proteins such as meat, fish, nuts, beans, pulses and seeds, dairy or alternatives

You should limit foods that are:

 High in fat and sugar as they are high in calories and do not have any extra vitamins or minerals

A healthy diet will also reduce the chances of getting heart disease and diabetes as well as other types of cancer and illnesses.

Tips for a healthy diet

- Eating the right amount to maintain a healthy weight
- Eating at least 5 portions of fruit and vegetables a day '5 A Day'
- Eating plenty of foods rich in fibre and starch
- Have some dairy or dairy alternatives (such as soya drinks)
- Include some beans, pulses, fish, eggs, meat and other protein
- Avoid eating too much fatty food
- Avoiding sugary food and drinks
- Avoiding alcohol or only drink in moderation

Further information is available from the NHS website Eat well - NHS (www.nhs.uk).

Exercise advice

- It is recommended that you should aim to be physically active every day. Any activity is better than none, and more is better
- Do strengthening activities that work all the major muscles on at least two days a week
- Do at least 150 minutes of moderate intensity activity or 75 minutes of vigorous intensity activity intensity activity a week (or a combination of both).
 - Examples of moderate intensity activity include brisk walking, riding a bike or mowing the lawn
 - Examples of vigorous activity include running, aerobics, playing football or riding a bike up hill
- Reduce time spent sitting or lying down and break up long periods of not moving with some activity

Regular physical activity will help prevent and manage over 20 chronic conditions, including cancer. Walking daily and building up the distance you walk is a good starting point.

You can talk to your GP, Cancer Nurse Specialist or visit the Macmillan website <u>www.macmillan.org.uk</u> about how best to get started and find out about activities in your area including walking for health groups.

For more information about the physical activity guidelines for adults, visit <u>www.nhs.uk-live-well-exercise</u>

Can I drink alcohol?

Once you have completed your treatment there is no need to avoid alcohol entirely. We would always advise that you should not drink more than the Department of Health's recommendations, which are to:

- Drink no more than 14 units a week
- Spread your drinking over 3 or more days if you regularly drink as much as 14 units a week

• Cut down by trying to have several drink-free days each week

Fourteen units is equivalent to 6 pints of average strength beer or 10 small glasses of low strength wine.

For more information visit www.nhs.uk-live-well-alcohol-support

Cancer Specific Information

My Personal Follow Up Plan

My Tests

Test	Year 1	Year 2	Year 3	Year 4	Year 5

My Results

Test Completed	Test	Test Date	Result Date	Test Result

National information

<u>Age UK</u>

Freephone advice line 0800 169 656 www.ageuk.org.uk

Cancer Research UK

Information and details of clinical trials. Helpline: 0808 800 4040 www.cancerresearchuk.org

Carers Trust

Telephone: 08448004361 www.carers.org

Carers UK Carers Line

Freephone 0808 808 7777 (Monday to Friday, 10am to 4pm) www.carersuk.org

Citizens Advice Bureau www.citizensadvice.org.uk

Dial UK

Local disability information and advice. Telephone: 0808 800 3333

www.dialuk.info

Disability Rights UK

Practical advice for people living with a disability or health condition. They provide access to more than 9,000 public toilets for disabled people in the UK via a Radar NKS Key which can be purchased from the Disability Rights UK online shop. www.disabilityrightsuk.org

Macmillan Cancer Support

Telephone: 0808 808 0000 (Monday to Friday, 9am to 8pm) www.macmillan.org.uk

<u>MIND</u>

A mental health charity which provides advice and support to empower anyone experiencing a mental health problem. <u>www.mind.org.uk</u>

NHS Carers Direct

Freephone 0300 123 1053 (Monday to Friday, 9am to 8pm; Saturday to Sunday, 11am to 4pm) <u>www.nhs.uk/conditions/social-care-and-support-guide</u>

NHS Choices

The site includes all NHS online services and information. www.nhs.uk

<u>Rethink</u>

A mental health charity which aims to improve the lives of people severely affected by mental illness through their network of local groups and services, expert information and successful campaigning. <u>www.rethink.org</u>

<u>Turn2us</u>

A UK charity that helps people access money which may be available to them, through welfare benefits grants and other help. Telephone: 0808 802 2000, (Monday to Friday, 9am to 8pm) <u>www.turn2us.org.uk</u>

<u>Walking for Health</u> is England's largest network of health walks with over 360 active walking schemes, helping people across the country lead a more active lifestyle. <u>www.walkingforhealth.org.uk</u>

Local information

My Wellbeing Space is a health and wellbeing website designed by patients and carers for patients and carers in the North East and North Cumbria. It provides lots of useful information and links to support people affected by cancer <u>www.mywellbeingspacenca.nhs.uk</u>

Cancer North

The Cancer Support VCSE Network North East is a collaboration of voluntary, community and social enterprise (VCSE) organisations in the North East who offer a range of services for people affected by cancer https://cancernnorth.org.uk

Acknowledgements

Thanks to the partnership of Macmillan and the Cheshire and Merseyside Cancer Alliance who have given permission to use the Southport booklet as a basis of this work.

Endorsed by:

Northern Cancer Alliance Public Involvement Accountability Forum January 2022

Updated in: March 2023