Life ahead plan
An aid to planning your long term recovery from cancer
This plan has been developed by the Living With And Beyond Cancer Patient and Carer Reference Group.

“The purpose of this document is to give you the opportunity to briefly reflect on your experiences and start planning for the future, your “life ahead”. This will include a period of further recovery and then a period of adjusting to your life beyond cancer.

Parts one and two are designed to be filled in immediately following completion of your treatment. Part three is designed to be completed in 12 to 18 months time. We hope you find this useful and don’t forget to ask your health care team if there is anything you can’t fill in or don’t understand”.

Members of the living with and beyond cancer patient/carer group at The Christie
Part One: Your Treatment so Far

This section will include an opportunity to note what treatment you have received and a chance to reflect on what has happened to you and how you feel about cancer.

Your consultant will be sending a letter to your GP and provide an ‘end of treatment summary’ once you have completed all the treatment that has been planned. This letter should also highlight what needs to be looked for in the future and the follow-up plan. You are, of course, entitled to a copy of any letter, but even if you do not usually bother, it is worth asking for a copy of this one. It can be kept as a useful record and a source of information.

**1.1: If you feel it is useful, make a note of what treatment you have received in the space below:**
1.2: Follow-up arrangements

If you feel it is useful, make a note of what your follow-up arrangements are, any further treatment you might be receiving and/or any investigations that might be planned:
1.3: A chance to reflect

Lots of things will have happened to you over the course of your recent treatment for cancer. Some may have felt very significant, some you would like to leave behind, all of it will be important. Why not take a few moments to reflect on what you know and how you are feeling, and write some comments in the boxes below:

How did I feel about cancer at diagnosis? Did this change during the course of my treatment?

What didn’t I ask that now seems important?

Despite having to deal with something as difficult as cancer, many people say that there have been some good things that have come out of it – would that apply to me?
Part Two: “I’ve just finished treatment, what next?”

This section will include short term post-treatment help and advice, help with guidance and goal setting, your wellbeing and other things related to the first 12/18 months post treatment.

2.1. What do I need to know for the next 18 months?

Let’s try to get a few basics down around the initial period post-treatment. Have a go at answering the following questions based on the information you may have received from your health care team, including the “end of treatment summary”.

Is there anything that my doctor has advised me to do? (this might include: cutting down on alcohol, stopping smoking, becoming more active, or eating healthier food).

Is there anything I need to put on hold for 12 to 18 months while I continue to recover?
Do I know when my first check-ups or follow-up appointments are?

How often will I see my specialist or nurse after that? Where will these appointments be?

What should I be looking out for? How will I know if a problem has developed?

It may be that I will not need to come back for face to face check-ups in the future. Do I know where to get help if I encounter any problems? Note the details below:
2.2. “Keep Calm and Carry On”

You now have a lengthy period of treatment perhaps with debilitating side effects behind you. The desire to just get back to normal is understandably intense.

It is all the more disappointing when certain side effects, such as fatigue, make the transition back to normal slower than expected.

Perhaps the psychological impact of all that has happened still needs to be digested and perhaps you feel you are about to lose that fighting spirit that helped get through it in the first place.

This section will help you to identify side effects that you may still have to take into account, as well as thinking of ways of coping with these side effects.

What side effects have I been advised may affect me in the next twelve to eighteen months?

What can I do to help myself cope with and manage these side effects?
How will I deal with worries about the cancer coming back? Do I know what to look for? Who can help me keep those normal worries in proportion so they do not take over?
2.3. Getting Back To Work

Apart from paying the bills, work can be very beneficial for mental health, self-confidence and therefore healing, but a balance between what your body needs and what you feel you have to do must be struck.

No matter how many people tell you to wait as long as possible with your return to work, you may not have this luxury. On the other hand, no matter how eager you are to get back to work your body may not be ready or you may have to move back more slowly than expected.

Keep in mind that from the comfortable seat of your couch, things seem achievable which really aren’t once you are in the situation.

Because of this, it is very important to take into account advice from your consultant, specialist nurse, physiotherapist or occupational therapist. This section is designed to help you do this, as well as work out what is best for your individual situation and what resources and advice are available to help you follow your personal path.

Have I received advice about going back to work? Have I discussed this with a healthcare professional? What was the outcome of the meeting? What resources might be able to help?
Have I discussed this with my employer? What was the outcome of that discussion?

If I am self-employed, will I be able to manage my expected workload? Have I considered getting some additional temporary help?
2.4. Goal Setting

So far, you have had things done to you and for you, now you might want to start thinking about what you can achieve yourself and set yourself some realistic and achievable goals over the short to medium term. These might be as simple as being able to walk a certain distance, or cooking a meal for the family, or it might involve rediscovering an activity that you enjoy. It may be useful to discuss this with friends, family and health professionals:

*Think about what the next steps are in the short term and write them down in the space below? What is my timeframe?*

*These are the people who will help and support me….*

*What am I going to treat myself with when I achieve my goals?*
Part 3: “Something has happened or changed, what do I do?”

This section will include long-term post-treatment help and advice, help with settling back into your routine, new problems that may arise and other issues related to your life ahead.

3.1 Another chance to reflect

Look back at Section 2.1. Now that you are 18 months further down the line, have things altered or changed that you may need to consider? Make a note of them below.

Are any of the actions and recommendations still relevant to me now? Which ones?

Are there any further check-ups or follow-up appointments that I may need to attend?
Is there anything I can now do that previously my doctor or nurse would have advised against? (See 2.1)

Are my coping strategies working (see section 2.2)? How have I incorporated them into my everyday routine? Are they still appropriate now?
3.2: “The new normal”

You’ve come a long way, and you may have a certain idea of what it means to get back to normal. For many people, it may not be possible to go back to exactly how their life was before cancer. However, it will be possible to reclaim many aspects of what you used to like doing.

If you smoke, you might want to seriously consider giving up. It’s never too late to enjoy the health benefits of not smoking. You might also want to consider reducing the amount of alcohol you drink and enjoying a more healthy diet. Becoming more active and doing regular exercise is highly beneficial and can reduce the risk of the cancer coming back.

There may be new things that you’ve now got the confidence and skills to try.

This section is going to help you think about what characterises your “new normal” and how you might go about achieving this.
What did I enjoy doing before my diagnosis, such as hobbies, sports, and interests? Make a note in the space below. What was it about these activities I really enjoyed?

Is there anything preventing me revisiting these activities? Or is there anything I could do instead that might make me feel the same way? Could relatives, friends or carers help me?

Is there anything new of different that I’d like to try? Have I already tried something different? How did it make me feel?
3.3: Late Effects

Most people have fears that their cancer may return. There is also a chance that you may encounter long term side effects from your treatment, or side effects that appear out of the blue many months or years after treatment. These side effects are called “Late Effects”.

This section will include an opportunity to think about possible late effects and where to get help. It will also help you decide what to do if you are scared your cancer may have returned.

Write down any possible Late Effects that my doctor or nurse may have explained may occur.

If I am feeling anxious about either cancer recurrence or late effects, do I know where to get help?
You might want to consider the following options:

- Making an appointment to see your GP.
- Approaching a local cancer support group – there are often support groups that cater for specific cancers in your local area or at your local hospital.
- Use online resources – the Christie has a dedicated website for people living with and beyond cancer.
- Call the Macmillan helpline on: 0808 808 00 00

Are there any tests that I might need to have every year or so because of the effects of treatment in the past?
3.4: Planning your financial future

Going through the experience of having cancer, including its financial impact, might have prompted thoughts about the importance of putting things in place that will help to ensure financial stability when faced with similar things that life may throw at you. At the same time, after a cancer diagnosis, some things, such as insurance, can come at a higher price or completely out of reach. This section is designed to help you establish what issues you would like to address with regard to your financial future and which options are available to you to help you with this.
Although I may have already thought about my finances, now might be a good time to review them – is there anybody I can speak to who can help me? Please note their details and comments below.

Travel insurance can be harder to obtain following a cancer diagnosis. Have I come across any particular deals or services that have made this easier or less expensive?

Some of us may be entitled to benefits and a benefit review. Have I spoken to someone as regards to this? - Perhaps the Benefits Advisor in my local hospital? Note their details and comments below.
3.5: Your Life Ahead

The templates in this guide have been put together by other patients. We are quite aware that we probably have not covered everything that you may be concerned with at this time. Therefore, the section below is a space for you to think about any other issues that you want to address and possible ways of addressing them. We have included one or two pointers in the first few boxes for areas you might want to think about, but there is also a space for your own, unprompted thoughts and reflection right at the end.

*Mental health is very important and many people suffer from stress, depression or anxiety. Take a moment to reflect on experiences and how I may have coped with these issues if I have encountered them. Note down where I can get help with these issues.*

*Family relationships – I might want to reflect on how my relationships have changed with members of my family and close friends. For example, perhaps one or other of them has been and will continue to be my carer. Take a few moments to note down my thoughts here.*
It can sometimes be difficult to talk about sexual relationships and sexuality with a healthcare professional and/or the family, but I may want to take time to reflect on any issues encountered here. It’s important to seek help and advice should I encounter any problems. Make a note in the space below.

Broadly speaking now, what three things would make my life healthier and better right now and for the future?
Remember

If you need urgent medical help in the future, even about an unrelated health problem or after an accident, show this leaflet to the nurses and doctors treating you.

Take this document home and keep in a safe place. It is a good idea to take this information with you when travelling outside the UK.

Visit the Cancer Information Centre:

The Christie at Withington Tel: 0161 446 8100
The Christie at Oldham Tel: 0161 918 7745
The Christie at Salford Tel: 0161 918 7804

Open Monday to Friday, 10am to 4pm.
Opening times can vary, please ring to check before making a special journey.

Macmillan Cancer Support have been working in partnership with The Christie NHS Foundation Trust since 2010 to develop the Life Ahead Plan with patients and carers.

Questions about living with cancer? Macmillan Support Line freephone 0808 808 00 00 (Mon - Fri 9am-8pm) www.macmillan.org.uk

Hard of Hearing? Textphone 0808 808 0121 or Text Relay.

Non-english speaker? Interpreters available.
More useful resources at: be.macmillan.org.uk

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