



Afterwards...

... recovering from the impact of cancer treatment

Recovery booklet, by Mike Osborn ©2012
Royal United Hospital (RUH), Bath, UK

Entitled:

“Afterwards ... recovering from
the impact of cancer treatment”

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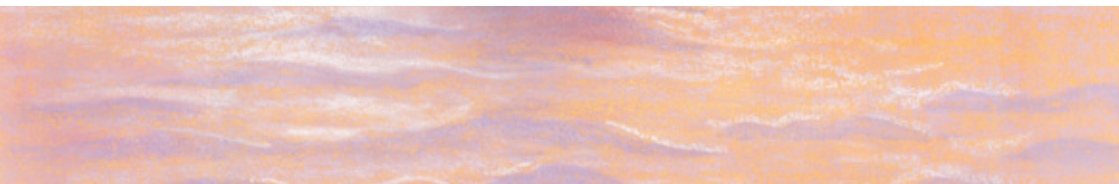
This booklet has been written by staff and patients of the RUH to describe the many thoughts and feelings that may visit you as you recover.

People are very different and nobody recovers in the same way so some of the things we describe may not relate to you, while others might.

It is helpful to know in advance what feelings you might feel after treatment, as you may never have had them before and they can be very strong.

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Introduction

Getting over treatment can be straightforward, but it is not easy for everyone. The impact of a cancer diagnosis and treatment can be very harsh. It can have a significant psychological effect on the person and those who know them.

Treatment can be unpleasant and many people are surprised at how long it can take before they feel more like their old self.

Knowing what's coming can be helpful. It helps to know a little about what to expect.

What are we like?

Keeping things to ourselves, not making a fuss

Most of our experience of illness and treatment is kept very private and invisible to everyone.

Because we tend to keep stuff to ourselves, most of the things we describe in this booklet are not shown in public. Most people put a lot of effort into keeping it that way.

People often try to protect their loved ones from how bad they feel at times.

We don't get to choose our feelings in advance. They arrive and we have to deal with them. Some of the feelings you will get post-treatment will be very powerful or unpleasant and may be new to you - but they are normal.



On the whole people don't talk much about the way cancer makes them feel. They can feel under pressure to be positive all the time and not to appear low or negative.

We don't talk about cancer much and it can be difficult for people new to treatment to know whether or not what they are feeling is normal.

Diagnosis... storm coming

The diagnosis of cancer can trigger off a massive feeling of shock. You can feel numb and confused and at times very scared and afraid for the future.

During that time your memory will be like a sieve and you will find it hard to focus on anything at times.

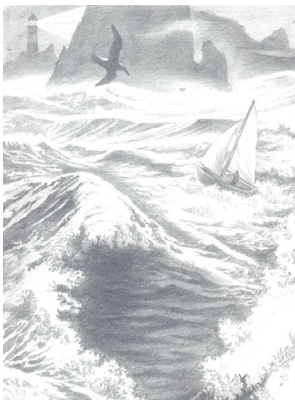
Hopefully, as treatment starts this feeling eases as you begin to feel that you are doing something about it.



Treatment

All cancer treatment – chemotherapy, radiotherapy and surgery - can be physically very harsh.

The whole process can be grim and draining. It has often been described as a battering experience.



Nausea, pain and worry can be very common and fatigue is almost inevitable.

Remember, chemotherapy visits every cell in your body, and surgery and radiotherapy also mean a serious assault on the body, so it's no surprise you can end up feeling exhausted and as weak as a kitten at times. Very thin-skinned.

Future... the way on

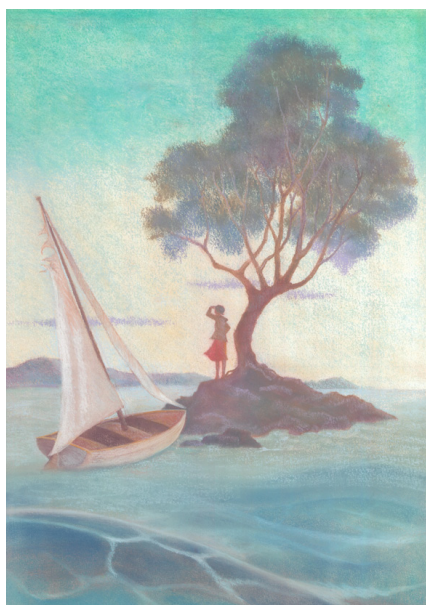
After the demands of treatment and the shock of diagnosis it can be a relief to be able to get back to feeling more normal and look forward to a more comfortable and healthy future.

Future... what now?

When treatment ends it can be a huge relief, but there can also be mixed feelings.

After the 'busyness' of treatment, and the daily or weekly contact, you can feel as if you've been abandoned.

The deafening silence afterwards can feel a bit strange and some people describe feeling isolated and lonely.



Gradually, as you recover your strength and the side effects of treatment ease, you will begin to get back to your everyday life.

The psychological recovery process is very individual and lasts a whole lot longer than the medical side of things. Some of the experiences that may visit you as part of the normal psychology of recovery are described below. It can help to know something about them in advance.

The Normal Psychology of Recovery ...what to expect

It helps to know a bit about how cancer treatment affects us as people, so you know what to expect.

An important thing to bear in mind is that recovery takes time - and usually a lot longer than you think.

You don't choose to have the feelings that you get as you recover: they just arrive and have to be managed.

People tend to put a lot of effort into keeping their feelings to themselves and not showing them to other people. They try to protect other people from how they feel.

You can't tell from the outside what anyone is feeling on the inside. This makes it difficult for people to know whether their feelings are normal.



You have nothing to compare it to.

Fatigue and exhaustion ...everything is an effort

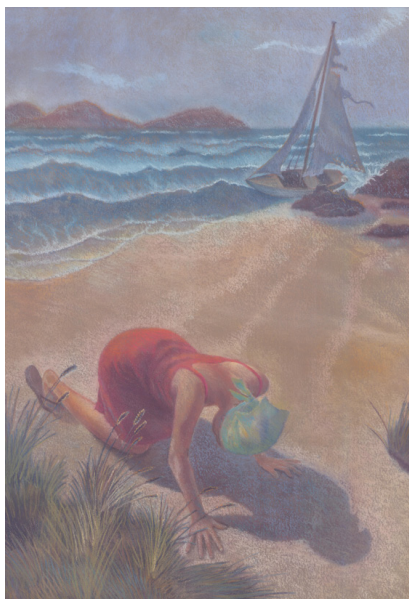
People who have been through treatment often describe feeling as if they've been through a battering experience. Physical and emotional fatigue are the most common symptoms of treatment and are often the last thing to improve.

After treatment you can feel very weak and will get tired easily. You can feel very weak afterwards, feel more sensitive to the cold or the heat, or more prone to widespread aches and pains.

Fatigue can affect the whole way you look at your everyday life. Lots of things, lots of little things you used to take granted, now take a lot more effort - even thinking and talking.

You may find at times that you don't have any enthusiasm for anything, feel flat, and have no get-up-and-go, no va-va-voom.

Fatigue may be the last thing to go – and it is important not to over-do things too early – but try to keep moving.



Memory and concentration interrupted ...being in a fog



Thinking takes effort, just like walking or doing anything physical.

Treatment causes fatigue which can slow up your thinking.

For a while after treatment you will have a memory like a sieve and at times you can feel as if you are walking around in a fog.

Forgetful, can't focus, can't concentrate, distracted. This will pass as you get your strength back, but it can be embarrassing for a while or make you lose confidence. If you really need to remember something, make sure you write it down.

Emotionality...

People vary enormously as to how emotional they are on a day-to-day basis. Most of these emotions are very private and nobody knows about them but you; we don't show all the feelings that we have.

Treatment, worry and fatigue can leave us feeling much more emotional than we were before. You may feel very 'thin-skinned'.



Worry...

There is a lot of shock, fear and uncertainty in cancer treatment and recovery.

Worry is where thoughts go round and round in your mind and you cannot seem to sort them out. They are often linked to physical feelings of anxiety and agitation.

Worrying can take up a lot of time and can be very tiring.

You can get very frustrated and angry at yourself about your worry, or become embarrassed about it if you think it means you are failing to cope.

People vary as to how much they worry – but everyone worries after treatment.



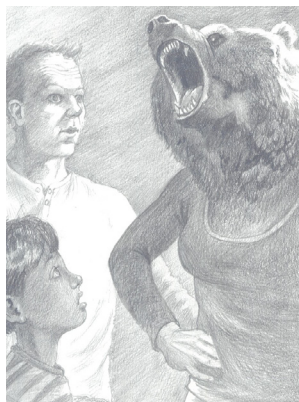
Withdrawal... and fear



After treatment, low self-confidence and a general feeling of apprehension can mean that you just want to hide away from people and 'lick your wounds' for a while.

You may not want to be around people too much and find that even family and friends wear you out very quickly.

...and anger



The shock and worry about cancer and the brutal assault of treatment can cause you to feel much more prone to waves of adrenaline and a kind of ongoing mini-panic where your body and mind race.

You can't settle and you feel snappy and angry, or like running away from everything.

This is called the fight and flight response and is a common symptom of treatment.

Intimacy and sexuality... feeling ugly

Treatment tends to make you feel unattractive and low in confidence. Some people even feel ugly and disgusted with themselves. This, plus the strain and fatigue of treatment can really affect your intimate relationships. Sex may be the last thing on your mind. Libido (sex drive) can be the first thing to go and the last thing to come back after treatment.

Sex is one of those things that people can find difficult to talk about. Getting back to enjoying a normal sex life can be a delicate matter. Often, partners are worried about bringing up the subject and not too sure how to go about it. This is particularly difficult if you have been left with some scars or ongoing pain. Your partner will worry about hurting you or upsetting you.

For some, sex is an important part of their relationship and quality of life. It can be an important part of feeling better about yourself, more like your old self and getting back to normal. Sex may be the last thing on your mind after treatment though, so don't rush into anything.



Other people...

Cancer affects families not just bodies. The love and care other people show you can be very moving and some of your relationships can become much stronger and deeper.

For some this may not always be the case ...

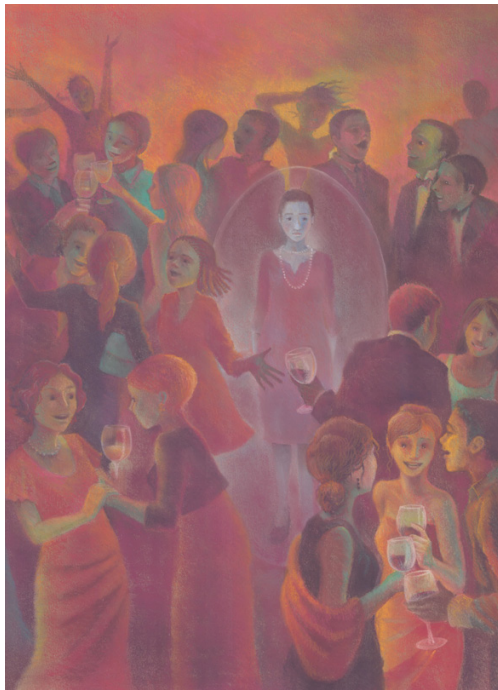
A lot of people find the whole subject of cancer too scary to think about.

Cancer can affect all of your relationships. On the whole we live in a society that is quite afraid of cancer and often people don't feel confident about what to say or do for the best.

The people you know well may vary widely in how they react to you and your illness. Some will become closer to you and very helpful, others will disappear and find it hard to be around you.

It can also be very difficult for you to know what to say to people about cancer. It is common to feel very awkward sometimes when you are in public or with people you know.

You will also find that being with other people will be one of the most tiring things that you can do. It will be important that you do not overdo it socially as you recover.



Identity ...

Serious illnesses like cancer, the treatments they involve, the way other people treat you and all the unpleasant side-effects that you experience can have an impact on your identity.

Your identity is a mixture of the way you think and feel about yourself and the way you think other people think and feel about you.

After heavyweight treatment you can feel as if you do not recognise yourself. You can feel quite subdued, withdrawn and your confidence can be low. Some people can feel ugly, ashamed, dirty or disgusted and afraid that other people find them repulsive or scary. This can affect the way you treat people and the way you treat yourself.



What helps...

Imagine...

Remember all the things you have been through since your diagnosis.

Now imagine it, as if it had happened to someone else.



Imagine that it happened to someone you love and respect.

How would you feel about them if they had been through what you have just been through?

What would they need to help them recover?

What do you need? What would a compassionate friend recommend for you?

Understanding...

It's important that you understand (as much as you feel you need to) about your treatment and that you feel involved in the whole thing.

It's also important that you understand how that treatment can affect people in many very normal, but unpleasant, ways. If you are confused about anything, please ask your team at the hospital or your GP.



The way you feel about yourself...

the way you think other people feel about you...

Treatment can be a very unpleasant experience. It can change the way you feel about yourself and can be a real test of how well you can look after yourself.

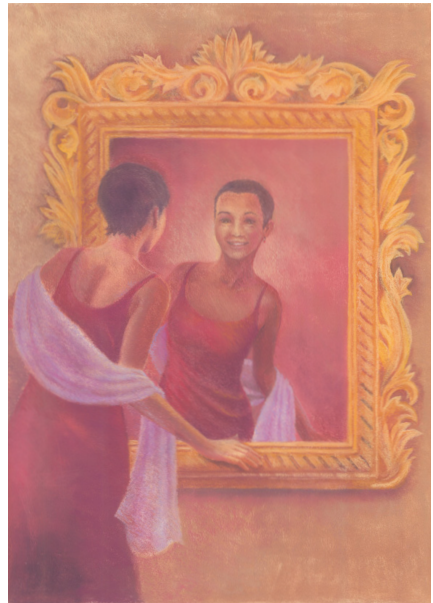
Recovering from treatment can also involve recovering your pride, your dignity and feeling comfortable when you are around people.

Remember that feeling bad is part of the impact of treatment, and takes time to shake off. Be careful not to be too self-critical, too self-neglectful or too self-attacking.

Try to treat yourself just as a compassionate friend would.

Try to remember that treatment involves not just unpleasant physical feelings but plenty of unpleasant psychological feelings too.

Stress, strain and anxiety, fear and worry are a big part of recovery from treatment.



Patience...

Everybody who recovers from treatment is always surprised at how long it takes before they feel back to their old self.

Medically you may recover in a few months. Psychologically it can take longer before the fatigue finally wears off.

Try to give yourself lots of time to recover. Don't be in a hurry. You will make most of the progress early on - but give yourself time to recover fully. It's worth having a one-year or a two-year plan for getting back on your feet.

Don't worry yourself or rush yourself through recovery. People don't recover quickly.

Ask yourself the question:

“ Would you let someone treat someone you love the way you are treating yourself at the moment? ”



Live well...

Recovery is a real test of how well someone can care for themselves. All the basics of living well apply more than ever, for example:

- good diet
- supportive relationships
- exercise and hobbies
- good stress management
- meaning and purpose in your life
- the self-compassionate approach
- not smoking, drinking or shopping too much

Make sure that you work, rest and play.

Give yourself the best chance to recover as early as possible by living well.

But be patient...



Ask for help...

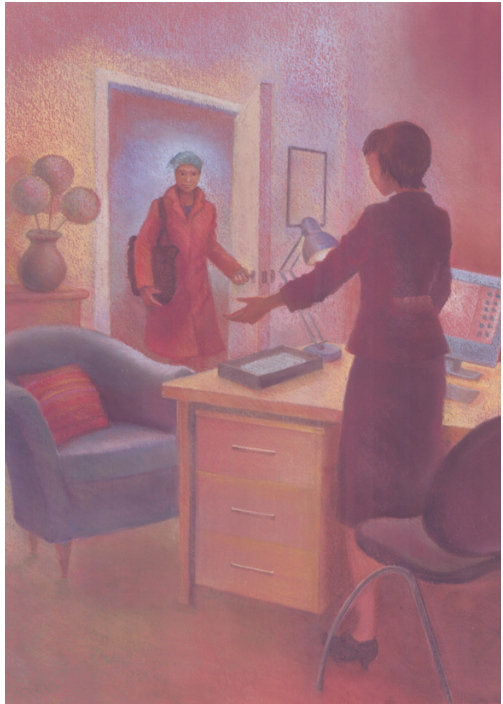
Although the many horrible things you can feel after treatment are very normal, they can be very powerful, very overwhelming, very distressing and very disabling. You can feel out of control and unable to decide what to do for the best...

You may find it helpful to ask for help.

Useful websites include:

www.cancer-uk.org

www.macmillan.org



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