



This information pack has been designed and written by the IOM Cancer Services User Forum, in conjunction with the Macmillan Cancer Information & Support Service and IOM Anti-Cancer Association.







We would like to thank
Ron Strathdee, Sylvia Constantine,
& Graeme Easton
for allowing us to use their photographs of
the Isle of Man.

Thank you also to

Macmillan Cancer Support
for allowing us to use their organiser as
a template for this information pack

About this information pack



This information pack is designed to help you keep all the information you may need about your cancer, treatment and the support services available on the Isle of Man, all in one place.

This information pack includes:

- Space to make your own notes
- A place for the health professionals looking after you to record down essential information for you to refer back to.
- A place to store all the information you are given

Use this as a diary, use it to write down all the questions you want to ask at your next appointment, use it to keep everything in one place — whatever works best for you.

Remember to bring this information pack along to all your appointments.

In the unlikely event that you need to go to the Accident & Emergency Department or MEDS (Out of Hours Emergency Doctor Service), please bring this information pack with you to show the medical staff, as the information may be useful to them.

Whilst we know it can be stressful and sometimes frightening, there are many people willing to help and support you and your family — you should never feel alone.

Never be afraid to ask for help.

Content – information pack



Section 1 – Your Important Information

Key contact details for the team looking after you, emergency contact details.

Section 2 – Your Notes for the Week Ahead

Diary section, with space for appointments, notes, information from the team looking after you.

Section 3 – A Cancer Diagnosis

What to expect at diagnosis, including practical tips from those who have been through the experience.

Section 4 – Cancer Treatment

Information on travelling off-Island for treatment.

Section 5 – Looking After Yourself & Those Around You Support with emotional concerns, financial concerns, and general tips on well being.

Section 6 – Feedback About the Service You Receive IOM Cancer Services User Forum and also contact details for feedback to the Department of Health & Social Care.

Section 7 – Life After Cancer Treatment

Information & support available once treatment has finished.

Section 8 – Useful Contacts

List of organisations on the IOM who can be of support.



Your important information



Your name:	
Noble's patient number:	
Clatterbridge patient number:	
GP name:	Telephone/Email:
Consultant name:	Telephone/Email:
Oncologist name:	Telephone/Email:
Clinical Nurse Specialists names:	Telephone/Email:

Your important information



Other useful contact you may have: (e.g. district nurse, social worker, care worker)

Name:	Telephone/Email:
Role:	
Notes: (e.g. based at Noble's Hosp	oital)
Name:	Telephone/Email:
Role:	
Notes:	
Name:	Telephone/Email:
Role:	
Notes:	

Your important information



Support outside of usual hours:

There may be occasions where you need advice about your cancer treatment when your GP surgery or the chemotherapy suite is closed:

24 Hour Chemotherapy Telephone Helpline

Tel: 0151 334 1155, then ask for Bleep 5555

Support and advice from experienced Chemotherapy Nurses on the management of chemotherapy side effects.

(Provided by The Clatterbridge Cancer Centre in conjunction with Macmillan Cancer Support.)

MEDS (Manx Emergency Doctor Service)

Telephone your own GP surgery number to contact MEDS, the Out of Hours Emergency Doctor Service, for advice or treatment.

Please show this information pack to the medical staff as the information may be useful to them.

The Team Looking After You



When you receive a cancer diagnosis, treatment, and after treatment has finished, you will meet different people whose role is to support you during this time. They are the team looking after you.

The team looking after you is sometimes referred to as the MDT (Multi-Disciplinary Team).

Each member of the team has a specific role. Here are some of the people you may meet:

- Consultant Surgeons Surgeons treat cancer with surgery and operate on specific parts of the body. For example, a gastrointestinal surgeon specialises in surgery on the digestive system and bowel.
- Medical Oncologist These are doctors who specialise in chemotherapy and other drug treatments. Chemotherapy is the use of anti-cancer drugs to destroy the cancer cells. Other drug treatments for cancer may include hormonal or biological therapies.
- Clinical Oncologist These are doctors who specialise in radiotherapy, chemotherapy and other drug treatments. Radiotherapy treats cancer by using high-energy x-rays to destroy cancer cells.
- Clinical Nurse Specialists These nurses have specialist knowledge of particular types of cancer and give information and support during treatment.

The Team Looking After You



- Radiographers Radiographers either take x-rays or give radiotherapy treatments. Treatment radiographers also give advice on skin care.
- Dieticians Dieticians give advice about eating and nutrition. They help people with cancer to maintain a healthy, well balanced diet.
- Physiotherapists Physiotherapists help to build people's physical fitness and improve their mobility, energy, strength, joint range, co-ordination and balance.
- Occupational Therapists Occupational therapists give advice about home adaptations or extra equipment that may make it easier for people with cancer to manage everyday tasks.
- Social Workers Social workers can arrange personal care at home for people living with cancer. This may include help with washing, dressing or meals. They can also offer advice on finances and benefits.
- District Nurses These are nurses who work within the community and visit people in their homes. They provide help, advice and support with all the practical aspects of cancer care. This may include dressing wounds, giving injections and helping manage stomas, catheters and feeding tubes.

The Team Looking After You



Not sure who to ask?

Macmillan Cancer Information & Support Service

Main Entrance, Noble's Hospital

Telephone: 01624 650735

Email: MacmillanCancerInformationCentre.Nobles@gov.im

Open: Monday–Friday, 9.00am – 4.00pm

(excluding bank holidays)

The Macmillan Cancer Information & Support Service provides a confidential, drop-in service for anyone affected by cancer. They provide:

- literature on all aspects of living with cancer
- internet access to guide people to the most appropriate information resources
- opportunities to discuss treatments, side effects and other cancer related issues in a comfortable area
- help with financial and practical matters (benefits, travel insurance etc.)
- over the phone information and support for those not able to access the service in person.
- Information on the LookAhead service, to support people affected by medical hair-loss.



Your notes for the week ahead



This section is like a diary, with a sheet for each week. It can be used to write down:

- Your appointments for the week
- Reminders
- Your thoughts for the week
- Any questions you may want to ask at your appointments.

There is also a section for the team looking after you to record the key information they have discussed with you. By asking for health professionals to write in this section, you will have a record of all the key points discussed to refer back to.

At some clinics, you may be given a form about your concerns to fill in, and your health professionals may write their notes on this.

Sometimes its hard to repeat back what has been discussed at an appointment to family members — it may be easier to let them read what your Consultant or Clinical Nurse Specialist has written...

This section only contains a few week by week sheets. You can get more sheets by contacting the Macmillan Cancer Information & Support Service (in the main entrance of Noble's Hospital).

Write the date on the top of each new weekly sheet in advance; then you can note down any appointment dates given to you on the right sheet

Your notes for the week ahead Cancer Servi



Week commencing: 28th September

Appointments:

Mon 28th - blood test 10.30am

Thurs 1st Oct – appointment

Dr Ibrahim 11am

Info from the team looking after you:

Patient now on 4th treatment of 6 and is feeling well, they have no pain.

Suggested a visit to dieticians for personalised diet tips and to Macmillan Centre to obtain the recipe book and building up diet booklets.

Follow up appointment booked for 4 weeks in Isle of Man and a scan will be booked for 3 months' time in Aintree when chemotherapy has finished.

Your notes for the week ahead



Week commencing: 28th September

My thoughts for the week:

Questions for Dr Ibrahim

- How long will radiotherapy take?
- Where can I find out about places to stay?

I feel that there have been some ups & downs this week — looking ahead to treatment is positive but also a bit scary...

Need to remember to make arrangement for looking after the dog if going away for treatment



Week commencing:	
Appointments:	
Info from the team looking after you:	



Week commencing:	
My thoughts for the week:	



Week commencing:	
Appointments:	
Info from the team looking after you:	



Week commencing:	
My thoughts for the week:	



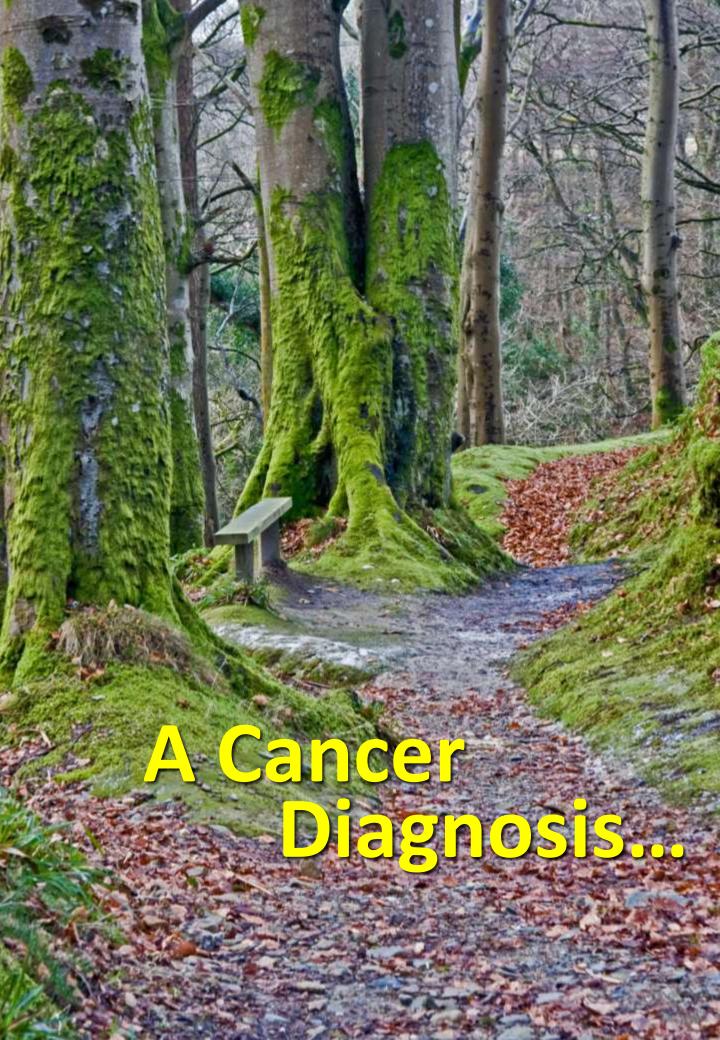
Week commencing:	
Appointments:	
Info from the team looking after you:	



Week commencing:	
My thoughts for the week:	



Week commencing:	
Appointments:	
Info from the team looking after you:	





Being told that you have cancer can leave you feeling a variety of emotions – shocked, numb, frightened....

Your Consultant, Clinical Nurse Specialist and GP can explain more about your cancer diagnosis, and answer any questions you may have.

The Macmillan Cancer Information & Support Service (in the main entrance of Noble's Hospital) is a good place to get further information about your particular cancer type.

Often there are loads of medical terms used when talking about cancer – if you don't know what they mean, ask.

You may feel overwhelmed by the amount of information you receive when you are diagnosed...

Ask the health professionals looking after you to write down the key points in this diary. You can read this again after your appointment and it can help when talking to others about your diagnosis.

Receiving a cancer diagnosis can lead to a rollercoaster of emotions.

Use the support available to you – don't feel you have to face this alone.



Here are some practical tips to consider when talking about your cancer diagnosis:

- Use this pack to write down any questions you want to ask – this way you won't forget anything important
- Bring a family member or friend along to your appointments. They can help with asking questions, providing support, and be an extra pair of ears to recall what was said.
- If you don't understand anything, ask your health professional to explain – don't be embarrassed to ask.
- Encourage your health professional to write down key information discussed for you to refer back to later.
- Think about what matters most to you share any concerns or worries with your healthcare team, then they will understand what is important to you.

Some people find it helps to write down their feelings about what is happening — you can use this diary in whatever way helps you best



Below are some common questions that are asked:

- What does my diagnosis mean?
- What happens next?
- Will my cancer spread?
- What tests and treatments will I have?
- What choices will I have about my treatment?
- Where will I have my treatment?
- How long will treatment take?
- How successful is the treatment likely to be?
- Will I still be able to work?
- Is there any support for my family?

Remember, your healthcare team may not know all the answers to your questions immediately.

Often, definite answers are not possible. With cancer treatment, there is often a lot of uncertainty.



Sometimes you will not remember everything you want to ask. Sometimes you will think of more questions after your appointment. Don't panic – you will get more than one chance to ask questions!

Use the support available from the team looking after you. You have the right to receive as much or as little information as you want – they are there to help you understand about your cancer diagnosis and treatment options.

There are many organisations that support people affected by cancer, their families and their friends. You can find more information about the range of support available in the Useful Contacts section of this information pack. Alternatively, the Macmillan Cancer Information & Support Service can help guide you to sources of support.





After diagnosis, the team looking after you will talk to you about the types of treatment that are considered best for you.

Your treatment plan should be discussed by a multidisciplinary team (MDT) of health professionals, and then the different options should be discussed with you.

The most common forms of treatment are:

- Surgery an operation to cut out the cancer cells.
 This may be done at Noble's Hospital or at a specialist cancer centre in the UK.
- Radiotherapy using radiation to destroy cancer cells. This is usually given at The Clatterbridge Cancer Centre.
- Chemotherapy using anti-cancer drugs to destroy cancer cells. This may be given at Noble's Hospital or at a specialist cancer centre in the UK.

You may have one type of treatment or a series of different treatments combined. The team looking after you will explain why they are recommending a particular treatment to you.

If you don't understand something, please don't be afraid to ask. It's important that you understand everything associated with your treatment options, so you can make an informed choice



Below are some common questions that are asked:

- Where will I have to go for my treatment?
- What are the risks and side effects of this treatment?
- How long will the treatment last?
- Will I be able to work whilst I am having treatment?
- How can you tell if the treatment is working?
- What happens after the treatment finishes?
- What can I do to help myself during treatment?

Travelling Off-Island for Treatment?

If your treatment needs to take place off-Island, the team looking after you should explain how this will happen. You will be issued with a **transport certificate**.

You will need to contact the Patient Transfers Department who will book your travel for you:

Patient Transfers

Suite D Ground Floor, Noble's Hospital, Braddan

Telephone: 01624 642673

Website: www.gov.im/categories/health-and-

wellbeing/patient-transfers/

Patient Transfers are there to support you through the process of booking your travel, what you need to do, and will be your contact for subsequent travel arrangements.



Travelling Off-Island for Treatment?

You should be given information on what costs you can claim back when you travel for treatment.

If you are going to the Clatterbridge Cancer Centre for your treatment, you may choose to stay outside the Hospital as an outpatient. If so, you will need to book your accommodation yourself.

For information about accommodation close to The Clatterbridge Cancer Centre, please contact the Macmillan Cancer Information & Support Service (in the main entrance of Noble's Hospital).

If you are concerned about the cost of travelling across for treatment, please discuss this with the team looking after you or the Macmillan Cancer Information & Support Service.

Don't forget to take your treatment diary with you at all times. It can act as a useful reference as to your treatment so far, and can also be completed by the health professionals you see in the specialist centre

When you return to the Island after your treatment, we would suggest that you contact the team looking after you and your GP to let them know you are back. You can discuss with them any questions you may have after treatment.



Your treatment is very individual and personal, and not every treatment is the same. You may speak to people who have experienced cancer treatment and they will give you their own personal advice. Whilst this can be useful and thoughtful, it is quite often not accurate for your own treatment. If you have any concerns over your treatment, please speak to one of the team looking after you.

This can be a testing time for you physically, mentally and possibly financially.

Do not be afraid to ask questions about assistance

Side Effects of Treatment

Cancer treatments can often come with side effects. Please talk through with the team looking after you the possible side effects that you may experience with your choice of treatment.

There is support available to assist with the side effects you are experiencing. Talk to the team looking after you or contact the Macmillan Cancer Information & Support Service for more information on the support available.

Looking After Yourself and Those Around You



Looking after yourself and those around you



A diagnosis of cancer can impact on all aspects of your life – you may have concerns not only about your treatment, but also money matters, work, relationships, your feelings....

Sometimes during treatment, things can seem out of your control.

Taking positive steps to help you to look after yourself can help you to feel more in control, and there are organisations who can help.

Emotional Concerns:

A cancer diagnosis can feel like a rollercoaster of emotions, and everyone responds differently to the ups and downs.

Some people find it helpful to talk to friends or family; or someone who has had a personal experience of cancer themselves – local support groups are listed in the Useful Contacts section.

There is also help available from:

Psycho-Oncology Service (Manx Cancer Help)

Counselling and psychological support. Manx Cancer Help offer a range of activities to support wellbeing.

Looking after yourself and those around you



Scholl Wellbeing Centre (Hospice IOM)

Counselling support.

Information drop-in held on Mondays & Thursdays 10.30am – 6.30pm at the Scholl Wellbeing Centre and on a Wednesday 10.30am – 6.30pm at Ramsey Town Hall.

These organisations also offer support to those who are caring for you during your cancer treatment, including support for younger family members.

The Macmillan Cancer Information & Support Service also have literature on dealing with the emotional impact of cancer.

There are people who can listen and support, don't think that you have to go through this alone.

Emotional Support Out of Hours:

If you need to talk to someone outside of office hours for emotional support, please contact:

Crisis Response Team (Mental Health Services) (01624) 642860

Samaritans (01624) 663399

Looking after yourself and those around you



Financial Concerns:

Work:

If you are working, you may need to take time off work for treatment and recovery. You will need to talk to your employer about what support they can offer during this time (e.g. reduced hours, flexible working, working from home). There is information available from the Macmillan Cancer Information & Support Service on work and cancer.

If you are self employed, or your employer does not pay for sick leave, you may be qualify for incapacity benefit from the Isle of Man Government.

Benefits:

The Isle of Man Government Social Security Office has a range of benefits which you may qualify for depending on your personal situation.

Some of the benefits available are:

- Incapacity Benefit
- Attendance Allowance
- Disability Living Allowance
- Income Support
- Employed Persons Allowance

Looking after yourself and those around you



Financial Concerns:

Benefits:

The Benefits Information Guide, available from the Social Security Office or Macmillan Cancer Information & Support Service, may help you decide which benefits are relevant to your personal circumstances.

Social Security Offices:

- Markwell House, Market St, Douglas, IM1 2RZ Telephone 01624 685685
- Cummal Mooar, Queen's Prom, Ramsey IM8 1EL Telephone 01624 812138

Age Isle of Man also provide advice and support with applying for benefits to those over the age of 50.

Other Financial Support:

If you have financial concerns, it may be beneficial to speak with an Independent Financial Adviser. Most Advisers will offer a free first consultation.

If you are in financial difficulty, you may be eligible for a Macmillan Grant or there may be other sources of financial support, e.g. grants from charitable organisations, available to you. For more information, contact the Macmillan Cancer Information & Support Service.

Looking after yourself and those around you



Financial Concerns:

Insurance:

After a cancer diagnosis, you may find it harder to get insurance. The Macmillan Cancer Information & Support Service has a list of travel insurance companies who provide cover to those with a cancer diagnosis.

Diet and Nutrition:

Following a healthy diet can have a beneficial affect both during and after cancer treatment. There is information available from the Macmillan Cancer Information & Support Service about diet and cancer.

Some cancer treatments may lead to either weight loss or weight gain. You may be referred to a dietician for advice about diet and weight. If you have concerns, please talk to the team looking after you.

Physical Activity:

During cancer treatment, you may not feel like you have much energy for exercise, but physical activity can have a positive impact on how you are feeling. It can help you manage fatigue, reduce stress, improve your mood, and many other beneficial effects.

Looking after yourself and those around you



Physical Activity:

Physical activity can range from walking and gardening, to exercise classes at the gym. Talk to the team looking after you about what type of activity would be suitable for you.

The Macmillan Cancer Information & Support Service has information on physical activity and cancer.

The Isle of Man Sports Development Unit provides support for those looking to improve their activity:

Website: www.gov.im/categories/leisure-and-entertainment/national-sports-centre/activities-for-adults/

Telephone: 01624 688556

Looking after those who support you:

A cancer diagnosis can impact on everyone around you. The support available is also accessible to those who care for you.

There are also specific organisations who provide support to carers:

- Crossroads Caring for Carers
- Hospice Isle of Man
- Manx Cancer Help

Full contact details are in the Useful Contacts section.



Feedback about the service you receive....



You may wish to tell someone about your experience of cancer services, positive or negative.

Feedback can help improve services for others in the future....

The Isle of Man Cancer Services User Forum are always interested to hear feedback from those who have had a personal experience of the Island's cancer services:

10M Cancer Services User Forum Telephone: 07624 498612 Email: csuf@manx.net

If you have any comments on this information pack, please let us know by contacting the User Forum or the Macmillan Cancer Information & Support Service.

If you are not happy with the service you receive:

The people looking after you will do whatever they can to make sure you are looked after, informed and empowered, and treated without delay. Sometimes however, things do go wrong and you may feel you wish to complain. If you are unable to complain yourself then someone else, usually a relative or a friend, can act on your behalf. It is important that you make your complaint as soon as possible and, where possible, share your problem with your health professional.

Feedback about the service you receive....



If you are not happy with the service you receive:

If you would like to talk to someone else or are not satisfied with the response, you can contact:

Noble's Hospital:

Patient Safety & Quality Team, Noble's Hospital,

Strang, Douglas, IM4 4RJ

Telephone: 01624 650793

Email: noblescomplaints.dh@gov.im

Family Practitioner Services:

Crookall House, Demesne Road, Douglas, IM1 3QA

Telephone: 01624 642613

Email: dh@gov.im

Community Health Services:

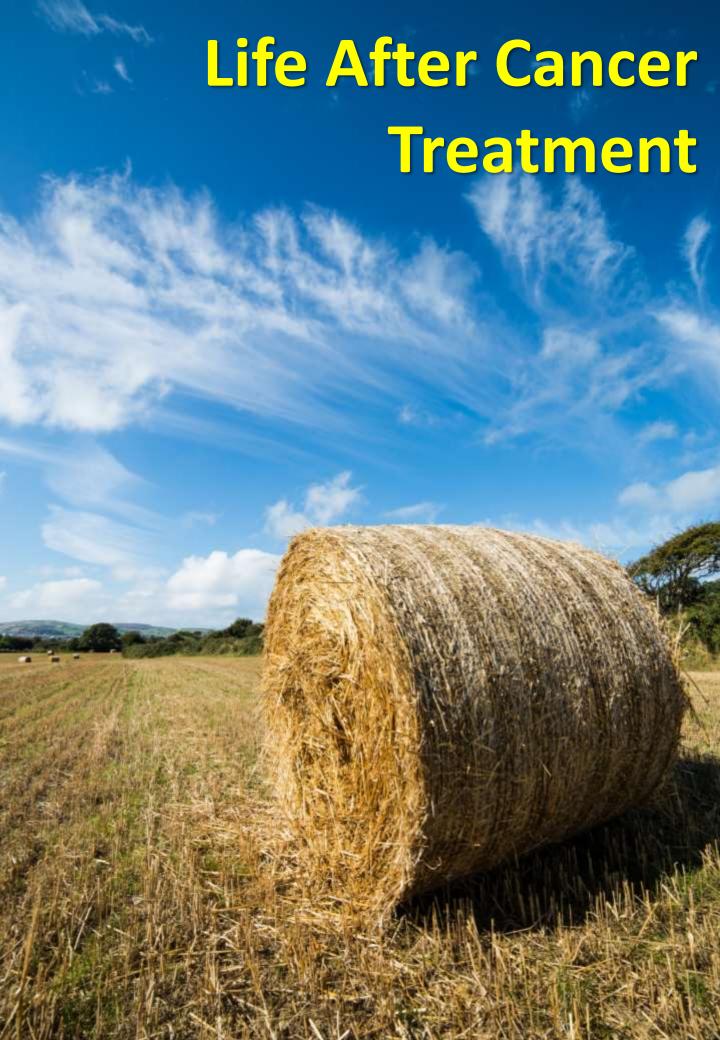
Patient Safety & Governance,

Community Health Services, Crookall House,

Demesne Road, Douglas, IM1 3QA

Telephone: 01624 642628

The Macmillan Cancer Information & Support Service can also put you in contact with organisations who can assist you with making a complaint.



Life after cancer treatment....



It is natural to look forward to the end of your cancer treatment – but what happens once treatment has finished?

I was looking forward to getting backto some sense of normalbut everything feels different...

It can be a challenging time as cancer treatment finishes. Moving on from regular appointments with the team looking after you, adapting back to everyday life and finding your new routine.

Every cough, niggle or twinge made me think that the cancer was back.

Please don't think that once your treatment stops you are on your own! If you need information and support after your treatment has finished, talk to the Macmillan Cancer Information & Support Service.

Knowing the other people had been through the same thing and come out the other side was really reassuring to me

Sometimes it helps to talk to other people who have also been through cancer treatment. There are organisations on the Island who offer specific support to those who have finished cancer treatment. This could be through support groups or through a survivorship group.

Life after cancer treatment....



There are a range of books and leaflets that may be of interest to you once your treatment has finished. These include personal stories of those who have also been through treatment, and information leaflets on looking after yourself once treatment has finished. The Macmillan Cancer Information Centre can show you what information is available.

Now the rollercoaster of cancer treatment has finished and I've got time to think about what has happened, its all feels a bit much to take in!

For some people, it is only when cancer treatment has finished that they have the energy to consider what they have been through. It is not unusual to experience a range of emotions at this stage.

There are organisations who can offer support from a listening ear through to more in-depth counselling and psychological support, depending on what is needed. For example, Hospice IOM offer a Survivorship course to support you once cancer treatment has finished. The Macmillan Cancer Information Centre can advise you about other organisations that can also offer support.

After cancer treatment has finished may also be the time to look at the positive steps you can take personally to move forward. This could include health & fitness, diet or just getting to know the "new" you... Use the information and support available to help you look forward.





Age Isle of Man

19 Drinkwater Street, Douglas, IM1 1AT

Telephone: 01624 631740

Website: <u>www.ageisleofman.org.im</u>

Services for those aged 50+, including information &

advice, activity clubs, and day centres.

Bowel Cancer Isle of Man

Telephone: 07624 480973

Email: bowelcanceriom@manx.net

Website: www.bowelcanceriom.com

Supporting those affected by bowel cancer, including a

monthly support group

Breast Cancer Now

Telephone:

Email: BCNowIOM@gmail.com

Website: www.breastcancernow.im

Information and support to those affected by breast

cancer.

Care in Mann

Telephone: 01624 628500

Volunteers who assist with transport for appointments

and other practical matters.



Crossroads Caring for Carers (Isle of Man)

Unit B5/B6, Eden Business Park, Cooil Road, Braddan

Telephone: 01624 673103

Website: <u>www.crossroadsiom.org</u>

Information and support for those who are caring for

someone, including respite care.

Cruse Bereavement Care

6c The Village Walk, Onchan, IM3 4EA

Telephone: 01624 668191

Email: info@cruseisleofman.org

Website: www.cruseisleofman.org

Support to anyone affected by a bereavement.

Isle of Man Breast Care

Nadine House, 13 North Quay, Douglas, IM1 4LE

Telephone: 07624 482662

Email: iombreastcare@manx.net

Website: www.iombreastcare.co.uk

Emotional and practical support to those affected by

breast cancer, including a regular support group.

Hospice (Isle of Man)

Strang, Douglas, IM4 4RP

Telephone: 01624 647400

Website: www.hospice.org.im

Specialist palliative care for anyone affected by cancer, supporting people from diagnosis through a range of services.



LookAhead

% Macmillan Cancer Information & Support Service

Telephone: 01624 650735

Support for anyone affected by hair loss due to chemotherapy treatment.

Look Good Feel Better

% Scholl Wellbeing Centre, Hospice Isle of Man

Telephone: 01624 647426

Skin care and hair loss workshops for those undergoing chemotherapy or radiotherapy.

Lymphoedema Support Group

% Hospice Isle of Man

Telephone: 01624 647456

Support for those affected by lymphoedema.

Macmillan Cancer Information & Support Service

Noble's Hospital, Strang, Douglas, IM4 4RJ

Telephone: 01624 650735

Email:

MacmillanCancerInformationCentre.Nobles@gov.im

Website: <u>www.cancer.org.im</u>

Information and signposting for anyone with a question relating to cancer.



Manx Breast Cancer Support Group

Telephone: 07624 484950

Website: <u>www.manxbreastcancersupportgroup.com</u>

Support and advice from those with a personal

experience of breast cancer, including hair loss advice

and use of the cold cap for chemotherapy.

Manx Swallows

Telephone: John Beckett 01624 827723

Doreen Wilkinson 01624 650229

Support group for those affected by cancers of the head and neck.

Manx Cancer Help

Lisa Lowe Centre, The Old School House, Cronkbourne, Braddan, IM4 4QH

Telephone: 01624 679544

Email: Info@ManxCancerHelp.org

Website: www.manxcancerhelp.org

Specialist psychological therapy, and other emotional support services, to anyone of any age affected by cancer

Patient Transfers

Telephone: 01624 642673

Website: www.gov.im/categories/health-and-

wellbeing/patient-transfers/

Tell us what you think!



We would love to hear your views on this Cancer Information Pack so that we can improve it for the future.

How would you rate the Cancer Information Pack? (*Please circle*)









Waste of paper

OK

Good

Very Useful

Who gave you for Cancer Information Pack?

At what point did you receive your Cancer Information Pack?

Which sections of the Cancer Information Pack have you found the most helpful? And why?

Tell us what you think!



Did your Health Profe Information Pack?	essionals writ	e in your Cancer No	
What other information Pack?	ion would yo	u include in this	
Any other suggestion	s?		

Please send or drop your feedback in to the **Macmillan Cancer Information & Support Service** Noble's Hospital, Strang, Douglas, IM4 4RJ