

Patient Initiated Follow-Up After Treatment For Primary Breast Cancer

Introduction

At your recent out-patient appointment with the Breast Team, it will have been explained to you that you are transferring onto patient-initiated follow-up (PIFU).

This type of follow-up has been specially designed, so you are more in control. It provides you with direct access to guidance when you most need it. Your normal routine will not be disrupted by regular routine hospital appointments; instead, you can quickly gain access to the Breast Team when you need to. It is based on evidence showing that there are no advantages to regular, fixed time follow-up in hospital for women and men that are well after treatment for breast cancer.

Who to contact for support?

Your Breast Clinical Nurse Specialist will be known to you since your diagnosis of breast cancer. The Breast Clinical Nurse Specialist is available at any point in your care and is still available whilst you are on Patient Initiated Follow-up. If you have any concerns about any new symptoms or need advice and support, you can contact them on the help line provided. For all other concerns, or if you are feeling unwell, your GP remains your first point of contact.

Two months following your last appointment you will be contacted by the Breast Clinical Support Worker by phone. They will discuss Patient Initiated Follow-up with you and any concerns or support needs you might have and offer you a Holistic Needs Assessment. Your Breast CNS will also make contact with you around 3 months' time to make sure you are feeling well and coping following your discharge from routine follow up. In the meantime, you should phone our helpline if:

- You have any symptoms that you are worried, might be a sign that your cancer has come back.
- You are having ongoing problems after your treatment that you need help with.

If the Breast Clinical Nurse Specialist thinks you should be seen back in one of our clinics, because of any symptoms you are experiencing, they will arrange an appointment for you to be seen within 2 weeks. If necessary, further investigations may be organised and a further out-patient appointment arranged to receive the results. Sometimes, verbal advice may replace the need for an outpatient appointment.

NB. The Breast Clinical Nurse Specialists are not in the office all the time, so please leave a message with your name and hospital number on the answer phone and you will be contacted within 2 days. This helpline is not for emergencies.

Helpline Numbers

Monday- Friday: 09:00-17:00

Eastbourne Hospital: 0300 131 4604 Email: esht.breastcnsedgh@nhs.net

Conquest Hospital: 0300 131 4833 or 0300 131 4834 Email: esht.breastcnsconq@nhs.net

Treatment Summary

Along with this leaflet you will receive a Treatment Summary. This provides information about your diagnosis and treatment. A Treatment Summary and information about Patient Initiated follow-up will also be sent to your GP.

Symptoms you may want to report

Most patients have no further problems or symptoms after they complete their treatment. Here is a guide to symptoms to seek further advice about:

- a lump or a swelling in your breast, in the skin after a mastectomy, above your collarbone or in the neck area, or under your arm
- any skin changes including dimpling, puckering, redness or raised spots on your breast or mastectomy scar
- nipple discharge
- if you develop Lymphoedema (affected side arm swelling)

Or if you experience:

- any new, on-going pain in any part of your body, especially in your back or hips, that does not improve with painkillers, and which is often worse at night
- pins and needles and / or a loss of sensation or weakness in your arms or legs
- unexplained weight loss and loss of appetite
- a constant feeling of nausea
- discomfort or swelling under your ribs or across your upper abdomen
- a dry cough or a feeling of breathlessness
- severe headaches- usually worse in the morning

Breast awareness and future mammograms

It is important to remain breast aware after your treatment. Being breast aware means knowing how your breasts or chest looks and feels. If you notice any changes that aren't normal for you, please contact your Breast Clinical Nurse Specialist.

The current recommendation is women and men should have **annual** mammograms for **five years** following a diagnosis of breast cancer. After your recent appointment your consultant will have arranged these appointments for you with Radiology. The appointments will be sent to you in the post **every year** or through my health record/Patient Knows Best, if you have registered online for this. *(Please see the end of leaflet if you would like to know more about accessing appointment letters and test results, online).*

After your mammogram, you will receive your results letter within **3 to 6 weeks**. For this reason, it is important to make sure that the hospital has your correct address and telephone number. If you do not receive your results within this timescale, please contact the Patient Initiated telephone helpline.

Sometimes, after having treatment for breast cancer, mammograms are not as easy to read; therefore, we may recall you so we can carry out further assessment or investigations. We will contact you by telephone if this is the case.

An NHS breast screening invitation is sent every three years to **all** women who are registered with a GP and are between the ages of 50 and 71 years. If you receive an invitation to attend an NHS screening mammogram, during the time you are attending the hospital for mammograms, **please cancel the appointment with the NHS Breast Screening Unit**. Inform them you are receiving regular mammograms at the hospital, after treatment for breast cancer.

At the end of the 5 years, you will be advised on when you will be offered future mammograms depending on your age and family history. Over the age for 71 you can self-refer to NHS breast screening program for three yearly mammograms by contacting the screening unit on 01273 664966

Anti-hormone therapy (Endocrine Therapy)

Some patients with hormone sensitive cancers are prescribed anti-hormone tablets, also known as endocrine therapy. You will usually be on these tablets for five years, although some patients may be advised to continue with their tablets for a longer period. Once you have been on Patient Initiated Follow-up for five years, the multi-disciplinary team will review your records and advise you of any changes to your medication.

Your **Treatment Summary** will confirm the date you started your hormone medication and the date you will complete your hormone therapy. Please contact your GP as you near the end of your hormone treatment.

Some patients will change their tablets at some point during their treatment. If you are one of these people, the date in which you are due to switch to another medication is confirmed on your **Treatment Summary**. If you become menopausal (your periods stop), you will sometimes be switched over to another anti hormone treatment at this point. If you think you are getting perimenopause symptoms, please see your GP for a hormonal level blood test and discussion about changing your medication

You will not have to pay for tablets as you are entitled to free prescriptions. A medical exemption certificate is available from your GP Practice.

Treatments do change and develop all the time; if there are major changes in the way we prescribe hormone medication during the time you are on it, we will write and tell you about this and what it may mean for you. We may request that you return to clinic to discuss this further.

DEXA scans

When you are taking an aromatase inhibitor such as Letrozole, Anastrozole or Exemestane you may need one or more bone density scans (**DEXA scans**). These scans can tell us if you are developing bone thinning which could lead to a condition called osteoporosis. These scans need to be arranged through your GP. Your **Treatment Summary** should tell you if these are required.

If your periods have stopped early because of your treatment, you may also need bone density scans. This can also be arranged by your GP.

Regular exercise such as walking as well as a diet high in calcium will help to maintain bone health, see end of leaflet for exercise advice.

Long term and late effects of treatment

If side effects of treatment do not go away, or if you develop late effects, you can contact the Breast Clinical Nurse Specialist; they can assess your symptoms and give you some advice on how to manage them.

As a result of taking Tamoxifen the lining of your womb may become thicker which can then cause you to develop vaginal discharge. This is common and not serious. However, if your periods have stopped and you experience unexpected vaginal bleeding, please contact your GP as you may need to be referred to a Gynaecologist.

To help avoid developing Lymphoedema, if you have had breast surgery and lymph-node removal, it is important to look after your arm. Lymphoedema is a swelling of the arm or hand. The following should be avoided to help you minimise your risk for its development. Avoid cuts, scratches, irritations, burns, wasp, bee and other insect bites. Don't have injections or blood given or taken on that side and avoid straining your arm or binding and squeezing the arm e.g. by a blood pressure cuff or tight clothing. If you notice any swelling in your arm, hand or chest, always ask your GP or nurse to check it. To rule out other causes and the earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully. It is also important to carry on with your arm exercises, shown to you by the Breast Clinical Nurse Specialist. Please see the end of leaflet for more advice on arm care.

Feeling unable to cope:

While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If you are finding it difficult to cope, your Breast Clinical Nurse Specialist may be able to arrange an appointment for one-to-one support or counselling. You can also self-refer to this service and your close family members can also receive support or counselling through this service. Please see details at the end of the leaflet.

Finally

If you are worried about something to do with your breast cancer, or the treatment that you have had for it, please contact your Breast Clinical Nurse Specialist. They would rather see you with something that turns out to be nothing, than for you to be at home worrying. There is some evidence that suggests cancer patients can feel very vulnerable when the active treatment stops, suddenly all the professionals around you disappear leaving you alone. It is important to build up a network of support around you; this can be achieved through support groups and exercise classes. At the end of this leaflet is a list of contacts and information where you can find other support.

Once you have been on Patient Initiated Follow-up for 5 years, the Multi-disciplinary team will review your records, if you have remained well and not required further interventions over that time they will discharge you from the hospital and Patient Initiated Follow-up to the care of your GP and practice team.

Support and useful contacts

Cancer Information and Support

- | | |
|--------------------------------------|-------------------------------|
| 1. Breast Clinical Nurse Specialists | 6. Finance and Social Support |
| 2. Body Image and recovery | 7. Macmillan Horizon Centre |
| 3. Cancer Register | 8. National Charities |
| 4. Complimentary Therapies | 9. Physical Activity |
| 5. Diet and Nutrition | 10. Support Groups |
| 6. Counselling & Emotional Support | 11. Personal Health Record |

1. Contact for Clinical Nurse Specialists

Eastbourne District General	Breast Clinical Nurse Specialists Heather Driver Emma Robb Katy Hollobon	Tel: 0300 131 4604 (with answerphone) Email: esht.breastcnsedgh@nhs.net
Conquest Hastings	Breast Clinical Nurse Specialists Juliette Twyman Louise Henham Shana Elphick	Tel: 0300 131 4833 or 0300 131 4834 (with answerphones) Email: esht.breastcnsconq@nhs.net

2. Body Image

Mammogram Appointment to Cancel or reschedule	Please ring the appointment Centre 0300 131 4600 Monday to Friday 08.00am-6.00pm Saturday 09.00am-12noon	Or Cancel or reschedule your appointment on-line https://www.esht.nhs.uk/service/out-patient-appointment/cancel-or-reschedule-your-outpatient-appointment/
Arm Care	This leaflet can help you regain arm and shoulder movement after breast cancer surgery. It has exercises for the different stages of your recovery and explains how to reduce your risks of lymphoedema. You need to follow this advice for life.	www.breastcancernow.org.uk https://breastcancernow.org/information-support/publication/exercises-after-breast-cancer-surgery-bcc6
Lymphoedema Service	Healogics provide 4 elements of treatment,	Referral by GP or Breast Clinical Nurse Specialist to

<p>(Treatment for arm swelling due to surgery or radiotherapy to axilla (armpit) as part of cancer treatment)</p>	<p>all of equal importance:</p> <ul style="list-style-type: none"> • skin care • exercise, • compression therapy (bandages or hosiery) and or • Simple Lymphatic Drainage (a special type of massage). 	<p>East Sussex wound healing and lymphoedema service who have NHS contracts to treat patients for Lymphoedema at their Centre in Eastbourne at their Centre in Hastings. They also see people privately</p> <p>East Sussex Wound healing and Lymphoedema service</p> <p>Wound Healing Centre Wish Tower House, 1c Edward Road, Eastbourne, BN23 8AS</p> <p>Phone: 01323 735588.</p> <p>Hastings referrals must go to Eastbourne site.</p> <p>Email for both: info@pioneer-whlc.org</p>
<p>Guidance on Pain</p>	<p>The British Pain Society - Provides contemporary guidance, supported by available evidence, on clinical and other pain matters.</p>	<p>http://www.britishpainsociety.org/people-with-pain/</p>
<p>Younger Women with Breast Cancer book</p>	<p>This book covers issues which may be important to younger woman such as:</p> <ul style="list-style-type: none"> • How treatment may affect your fertility • What happens when you are diagnosed with breast cancer during pregnancy • The impact a breast cancer diagnosis can have on your body image and sexuality and how this may impact upon relationships as well as practical advice about contraception. 	<p>www.breastcancernow.org.uk</p>
<p>Flat friends UK</p>	<p>Flat Friends UK - is dedicated to supporting women who have had single or double mastectomy surgery without breast reconstruction, including those who may face such decisions now or in the future, due to either a breast cancer diagnosis or preventative surgery. We believe living without reconstruction is a positive outcome. We have a closed Facebook group which provides a safe, private, respectful and</p>	<p>https://www.flatfriends.org.uk/</p>

	mutually supportive place for women to come together and talk about practical and emotional matters related to living flat, including clothing, cancer treatment and relationships in everyday life. Join us via our public page on Facebook, from which you can reach the closed group.	
Keeping Abreast	Keeping abreast recognises a great need for women, both newly diagnosed with breast cancer and facing the possibility of mastectomy, and also women further down the line who are also considering reconstructive surgery, to be able to meet and talk to other women who have been through similar experiences. This allows women make an informed choice about whether or not to proceed with breast reconstruction. They aim to provide information, support, practical help and advice for those considering breast reconstruction, including the opportunity to share the experiences of others. Also to enrich the quality of care for those recovering from breast reconstruction.	https://www.keepingabreast.org.uk/
Breast Prosthetic Fitting Conquest	The Orthotics Department have trained staff that will provide breast prosthesis. A clinic is held on alternative Friday mornings, by a representative from Silima, who will provide bra and prosthesis, fitting and advice.	Tel: (01424) 755255 ext. 14 8547. You will need to ask your GP to write a letter to the Orthotic Office to request a new prosthesis.
Breast Prosthetic Fitting Eastbourne	A prosthetics fitting clinic is held once a month on a Friday in a private room in Paget House at Eastbourne District General, where a representative from Silima, will provide breast prosthesis and advice on appropriate bras. Appointments are always required for prosthetic fittings. Each appointment lasts for 20 minutes. Occasionally more than one appointment is necessary to get a correct fitting.	As you have been discharged from the clinic your GP will need to send a referral letter to the Breast Clinical Nurse Specialists who will arrange the appointment for you.
Knitted knockers	Knitted Knockers - are a UK charity that knit and crochet breast prostheses for women that have undergone a mastectomy or lumpectomy. Ladies that have undergone surgery are provided with silicone breast prosthesis by the NHS, which some ladies	https://www.knittedknockersuk.com/

	<p>have found to be uncomfortable, heavy and may rub against the scars left after surgery, causing rashes and pain. At Knitted Knockers UK we want women to know that there is a lightweight, 100% cotton alternative that takes the form of a real breast and is soft against the skin and is breathable. Each Knocker is Made with love and filled with hope, and we provide them FREE OF CHARGE to those ladies who need it. Aqua Knockers are also popular and allow ladies to swim in confidence.</p>	
Breast Reconstruction Women	<p>If you have had a mastectomy and decided against reconstruction but change your mind at a later date, please contact Breast CNS's to discuss delayed reconstruction. If you had radiotherapy, we will advise you to wait at least a year after completion of radiotherapy. In some cases surgery can be offered to correct unequal breast sizes and you can be seen back in clinic if you wish to discuss this further. It is natural for breasts (treated and untreated) to change over time.</p>	<p>Eastbourne DGH Email: esht.breastcnsedgh@nhs.net</p> <p>Conquest Email: esht.breastcnsconq@nhs.net</p>
Men Chest Reconstruction	<p>Sometimes surgery can be offered to create a new nipple, the surgeon might be able to create the shape of a nipple using the skin from another part of your body (a skin graft). You can be seen back in clinic if you wish to discuss this further.</p> <p>Other options include tattooing a new nipple and areola on to the chest. Or you can use stick on nipples. Your Breast Clinical Nurse Specialist can tell you where to get them</p>	<p>Eastbourne DGH Email: esht.breastcnsedgh@nhs.net</p> <p>Conquest Email: esht.breastcnsconq@nhs.net</p>
3. Cancer Register		
Cancer Register	<p>Cancer Register - Leaflet explaining the Cancer Register and how information on all cancers across England can be tracked and monitored to help with research</p>	<p>https://s3.eu-central-1.amazonaws.com/pkb-uploads-nocrypto-eu-prod/47a79604ad0b40f5abbc206e86b5b119_cancer_registration_information_leaflet_jan19.pdf</p>
4. Complimentary Therapies		
Holistic Therapists	<p>The Federation of Holistic Therapists (FHT) is the UK's largest professional association</p>	<p>https://www.fht.org.uk/about-us</p>

	for therapists, ensuring high standards in therapy education and practice since 1962 below are some on line tips.	
Meditation	At a time when everything feels up in the air, it is important to put our own health and wellbeing at the top of our agenda. The ancient art of meditation can help decrease stress and lower blood pressure and is an easy practice to try at home. To get you started, we've put together a list of some free meditation practices to try.	https://blog.fht.org.uk/2020/03/30/meditation-to-try-at-home/
Yoga Tips for Anxiety	Leading yoga instructor and health and fitness specialist Hannah Barrett shares her expert tips to help with coronavirus anxiety.	https://blog.fht.org.uk/2020/04/08/yoga-expert-shares-tips-to-aid-anxiety/
Face Massage	A simple face massage which can be practiced daily to achieve brighter skin and to help alleviate headaches.	https://blog.fht.org.uk/2020/04/20/fht-vice-president-mary-dalgleish-shares-simple-face-massage/
Manage Stress	self-help techniques to reduce anxiety and boost your health and wellbeing	https://blog.fht.org.uk/2020/03/20/self-help-techniques-to-boost-your-health-and-wellbeing-at-home/
Hand Reflexology	A mini hand reflexology treatment, that you can apply to yourself anywhere, at any time, including in the comfort of your own home. It lasts just six minutes per hand and works different reflex points to help ease away stress and anxiety.	https://blog.fht.org.uk/2020/04/15/kate-mulliss-mfht-shares-a-hand-reflexology-video-for-stress-awareness-month/
Sleep Meditation	Meditations sleep stories, movement exercises, journals, and music. All of the resources on this page are free to use, and to share.	https://www.calm.com/blog/take-a-deep-breath
NHS Mindfulness	NHS Mindfulness Moodzone	https://www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/
NHS Help stress and Anxiety app	Stress & Anxiety Companion helps you handle stress and anxiety on-the-go. Using breathing exercises, relaxing music and games designed to calm the mind, the app helps you change negative thoughts to help you better cope with life's ups and downs.	https://www.nhs.uk/apps-library/stress-anxiety-companion/
5. Diet and Nutrition		
Healthy Eating	British Nutrition Foundation - For general information on healthy eating -	http://www.nutrition.org.uk/ Tel: 020 7557 7930

Complimentary approaches to diet	Penny Brohn Cancer Care - Offers complimentary approaches and self-help techniques including the 'Bristol Approach' for living with cancer including their approach to diet -	http://www.pennybrohncancercare.org/ Tel: 0303 3000 118 & press 1
Meals on Wheels Service	Wiltshire Farm Foods – Meals on Wheels Service	https://www.wiltshirefarmfoods.com/ Tel: 0800 077 3100 or fill out online enquiry form
Healthy Eating	Macmillan Healthy Eating and Cancer guide	https://be.macmillan.org.uk/Downloads/beMacmillanPDFs/MAC13612_Healthyeating_E03_LOWRES_20200206_KA.pdf
Eating Problems	Macmillan Eating Problems and Cancer Guide	https://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC13613E03NEating-problemslowresPDF20190325.pdf
Building up diet	Macmillan - The Building-up Diet Guide	https://be.macmillan.org.uk/Downloads/beMacmillanPDFs/MAC13614_Buildingupdiet_lowres_E03_P08_20200206_KA.pdf
6. Counselling and Emotional Support		
Counselling one to one support	Counselling and one to one support - This service is for anyone locally who has a connection to cancer, either they or a close family member have been diagnosed or are under investigation or have been bereaved through cancer.	https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre Counselling Helpline: 07747 472657 (phone or text) Email: lorna.earl@nhs.net
Younger Women with Breast Cancer book	This book covers issues which may be important to younger woman such as: <ul style="list-style-type: none"> • How treatment may affect your fertility • What happens when you are diagnosed with breast cancer during pregnancy • The impact a breast cancer diagnosis can have on your body image and sexuality and how this may impact upon relationships as well as practical advice about contraception. 	www.breastcancer.org.uk

Macmillan Horizon Centre – Virtual Sessions	<ul style="list-style-type: none"> • Anxiety Management Virtual Session • Mindfulness Virtual Session • Life Coaching – one to one online sessions. 	https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre
Counselling Sessions – Horizon Centre	<p>The Macmillan Horizon Centre Psychological Therapy Service. This service supports patients, family members and carers from 6 months after treatment has finished. Counselling sessions are still running and are being conducted over the phone or as online video sessions until face to face support can resume□</p>	https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre
BSUH Counselling, Psychotherapy and hypnotherapy	<p>The Brighton and Sussex University Hospitals Macmillan Psychological Therapies Service This is a free counselling, psychotherapy and hypnotherapy service available for cancer patients and immediate family members / carers during and up to 6 months post-treatment, that is currently offered via telephone and online (video).</p>	<p>Referrals to this service can be made via the Sussex Cancer Centre specialist nurses or oncologists. It will resume as a face to face service as soon as it is safely able to do so after the coronavirus outbreak.</p> <p>For further information contact: Laura Pritchard- Macmillan Lead for Psychological Therapies.</p> <p>Tel: 01273 664694.</p> <p>Email: laura.pritchard9@nhs.net</p> <p>Secretary: Hannah O’Neill.</p> <p>Tel: 01273 696955 x 64226. Email: hannah.o’neill@nhs.net</p>
Support Charity	Penny Brohn Cancer Care - Offers complimentary approaches and self-help techniques	Tel: 0303 3000 118 and press 1 or complete online enquiry form
Relationship advice and support	Relate- offer a range of services to help you with your couple and family relationships, whether young, old, straight, gay or bi, single or in a relationship - find a service near you	https://www.relate.org.uk/sussex
Support for a young person when a family member is diagnosed with a life threatening illness	Hope Support Service - supports young people when a close family member is diagnosed with a life-threatening illness, such as cancer. Health professionals can use online referral form – permission needed from parent/guardian if child under 16. Contact number - 01989 566317	http://www.hopesupport.org.uk/ Health professionals can use online referral form – Permission needed from parent/guardian if child under 16. Tel:- 01989 566317

Support for teenagers who have a parent with Cancer	RipRap - Website developed especially for teenagers who have a parent with cancer.	http://www.riprap.org.uk/ NOTE: RipRap is no longer funded and is led by one Clinical Nurse Specialist so there may be a delay in getting a response.
7. Finance and Social Support		
Finance- Macmillan grant	If you have cancer, you may be able to get a Macmillan Grant to help with the extra costs of cancer.	Tel: 0808 808 00 00
Macmillan Welfare Benefits	<p>The service offers free and impartial advice on the full range of welfare benefits. They offer benefits entitlement assessment, help to claim benefits (completion of forms), challenge decisions including appeals, access Macmillan grants and other charitable funds.</p> <p>Initial telephone appointments but face to face appointments at home or community venue arranged where appropriate.</p> <p>One-off advice or on going case work as required.</p> <p>Signposting of other financial and debt problems to appropriate free organisations where required</p>	<p>https://www.macmillan.org.uk/in-your-area/local-dashboard/detail/Benefit%20advice%20services/8261/Macmillan-East-Sussex-Welfare-Benefits-Advice-Service?proximity=0.10%20miles%20from%20you</p> <p>Catchment area: East Sussex.</p> <p>Location: 2nd Floor, 182-184 Terminus Road, Eastbourne, BN21 3BB</p> <p>Opening times: Office hours: 9am-5pm, Monday-Thursday, 9am-4pm, Friday.</p> <p>Tel: 01323 635989</p>
Social Prescribers	<p>Community Connectors - work in partnership with GPs in Hastings, Rother, Eastbourne, Seaford and Hailsham to help people access local services and activities that can help their health and wellbeing</p> <p>Areas they can support you to connect with include: • Healthy lifestyles and active lives • Arts, music, outdoors and creativity • Befriending, counselling and other support groups • Housing, benefits and financial support and advice • Employment, training and volunteering • Education and learning • Getting involved in local groups and activities • Accessing specialist services and support.</p>	<p>https://www.southdown.org/CommunityConnectors</p> <p>Email: social.prescribing@nhs.net Tel: 01323 340 151</p> <p>In addition to direct referrals from GPs they also accept self-referrals.</p>
National Energy Action Free Advice on energy suppliers/benefits	National Energy Action - The national fuel poverty charity and we can provide free, impartial one to one advice on energy related problems, switching supplier, understanding bills, tariffs, rebates, energy efficiency, mould and condensation, supplier issues, energy debt, Trust Fund applications, extra support for vulnerable	http://www.nea.org.uk/ Tel: 0191 261 5677

	people, income maximisation, benefits advice and lots more.	
WOLO (We Only Live Once)	WOLO (We Only Live Once) is a new charity based in Seaford - they aim to help families through cancer treatment. Donated funds are used to pay for services and experiences to help make the day-to-day lives of families affected by cancer easier. Each of the families they are supporting has very different on-going needs and they aim to support them every way they can through various means. Regular cleaning, complimentary therapies, annual passes for local attractions (to help create memories as well as have somewhere to go to have a much needed 'break' from cancer), gardening, childcare, legal and fundraising help - to name just a few. They help families in practical ways to help make their cancer journeys that little bit easier.	https://wolofoundation.org/
Equipment and products for older people to keep independence	Red Cross - Provides information and support, equipment and products for: older people who want to remain independent, disabled people of all ages, families, carers and health professionals:	http://www.redcross.org.uk/ Tel: 0300 456 1914
Befriending Service	Royal Voluntary Service - Offers help to older people who wish to maintain their independence and stay involved in their community. Provides a befriending service. Contact number - 01903 257019 or complete online enquiry form.	http://www.royalvoluntaryservice.org.uk/ Tel: 01903 257019 or complete online enquiry form
Carer's Advice	The Carer's Trust - Provides information, advice and support services to carers.	http://www.carers.org/ Tel: 0844 800 4361 Email: info@carers.org
Pet Sitting	The RSPCA - Provides help with pet sitting and local services	http://www.rspca.org.uk/
Pet Care when in hospital	The Cinnamon Trust - A charitable organisation that has 4,500 registered volunteers across the UK. They may be able to help you find pet care if you have to go into hospital or are too ill to care for your pet.	http://www.cinnamon.org.uk/ Tel: 01736 757900
Help for families with a child under 5 years	Home-Start UK - Offers support, friendship and practical help at home to families with at least one child under five who may be experiencing difficulties in their family lives due to illness or other reasons. □	http://www.home-start.org.uk/ Tel: 0116 4645490 info@home-start.org
Local Authority	East Sussex County Council - for health and social care support - they can advise and help with meals, care and support at your home or help to adapt your home. Home	https://www.eastsussex.gov.uk/ Different phone numbers are available, depending on help required, these can be found on

	adaptations include things like grab rails, ramps and stair lifts. The council can also help with housing, fire safety checks and lifeline monitors	the County Council webpage and are open between 08.30 to 5pm Monday to Thursday and to 4.30pm on Friday
Patient advice and Liaison -PALS	The patient advice & liaison service (PALS) Hastings	https://www.esht.nhs.uk/service/patient-advice-and-liaison-service/ Tel: Conquest: 0300 131 5309 Tel: Eastbourne EDGH: 0300 131 4789 Email: esh-tr.palsh@nhs.net
Help with welfare benefits and grants	Turn2Us - National charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services	http://www.turn2us.org.uk/
Hotel for Cancer Patients	The Grove, Bournemouth - A unique, luxury hotel by the seaside especially for cancer patients and their family, carers, or friends.	https://www.thegrovebournemouth.co.uk/ Operates on a not-for-profit basis, staffed by clinicians. Tel: 01202 552233 Email: enquiries@thegrovebournemouth.co.uk
Surrey and Sussex Cancer Alliance	Surrey and Sussex Cancer Alliance, working to improve Outcomes and experiences for patients In Surrey and Sussex.	Website https://www.surreyandsussexcanceralliance.nhs.uk Email Contact Rsch.sscadmin@nhs.net
8. Macmillan Horizon Centre		
Macmillan Sussex Support and advice Centre	Macmillan Cancer Support together with Sussex Cancer fund has built an innovative new information and support centre for people affected by cancer across Sussex Opening times: Between 09:00 and 16:30 Monday to Friday	https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre Tel: Tel: 01273 468770 Email: Horizoncentre@macmillan.org.uk
8. National Charities		
Marie Curie	Marie Curie - Marie Curie is a registered charitable organisation in the United Kingdom which provides care and support to people with terminal illnesses and their families.	https://www.mariecurie.org.uk/
Cancer Research UK	Cancer Research - Cancer Research UK is a cancer research and awareness charity in the United Kingdom and Isle of Man. As the	https://www.cancerresearchuk.org/

	world's largest independent cancer research charity it conducts research into the prevention, diagnosis and treatment of the disease.	
Macmillan Cancer Support	Macmillan Cancer Support - Macmillan Cancer Support is one of the largest British charities and provides specialist health care, information and financial support to people affected by cancer. It also looks at the social, emotional and practical impact cancer can have, and campaigns for better cancer care.	https://www.macmillan.org.uk/
Breast Cancer Now	Breast Cancer Now - is a charity which is available for anyone affected by breast cancer, the whole way through, providing support for today and hope for the future. Breast care nurses, expertly trained staff and volunteers, and award-winning information is all there to make sure anyone diagnosed with breast cancer gets the support they need to help them deal with the physical and emotional impacts of the disease.	https://breastcancernow.org/

9. Physical Activity at Home and Gym

Horizon Centre - Physical Activities at Home	Physical activity sessions from home These are virtual sessions using Microsoft Teams. This is very easy to use – just give them a call and they can help you get set up!	https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre#physical_activity_sessions_from_home If you would like to attend any of the online sessions please call Tel: 01273 468 770 or email horizoncentre@macmillan.org.uk
Pilates	Pilates (Horizon Centre) – Monday, 13:00-14:00 Join for friendly, gentle and relaxed Pilates sessions. Trouble getting up from a chair? Struggling more with your shopping? These Pilates-based moves could really help. Build strength, improve balance and increase flexibility. With plenty of laughter along the way too!	If you would like to attend any of the online sessions please call Tel: 01273 468 770 or email horizoncentre@macmillan.org.uk
Yoga	Yoga Nidra (Horizon Centre) – Mondays, 11:00-11.30 Please join this 30 minute session of virtual Yoga Nidra – sometimes called 'yoga	If you would like to attend any of the online sessions please call Tel: 01273 468 770 or

	sleep'. It is guided by meditation.	email horizoncentre@macmillan.org.uk
Breathing Workshop	Breathing workshop (Horizon Centre) – Wednesdays, 14:00 – 15:00 Our breathing workshop is a chance to learn how to use your breath to help you to relax and feel calmer. Our expert volunteer will lead you through the workshop sharing with you techniques and breathing sequences that you can then use whenever you need to take a breather.	If you would like to attend any of the online sessions please call Tel: 01273 468 770 or email horizoncentre@macmillan.org.uk
CU Fitter	CU Fitter - Self-referral exercise programme for people in cancer recovery. Online 'virtual' classes available during Covid-19 pandemic	http://www.cancerunited.org.uk/
Active Outlook	Active Outlook - is a free personalised physical activity programme in East Sussex and Brighton and Hove to help anyone living with and beyond cancer to prepare physically and mentally for their cancer treatment, help manage side effects of treatment and help support their recovery. Free, specialist support including one-to-one and group classes (remotely and face-to-face) Their coaches understand cancer and can create a physical activity programme just for you, as well as giving you ongoing support. Active Outlook is available to anyone at any stage of treatment or fitness level.	SCF Active Outlook – Physical Activity Programme - Sussex Cancer Fund Referral through your healthcare provider or self-refer online
Freedom Leisure	Freedom Leisure offer specific exercise classes led by a specialist cancer trained instructor. Benefits include: Group support, increased stamina, strength, flexibility and well-being, increased confidence. Classes take place in a fun, sociable environment with a range of activities available.	https://www.freedom-leisure.co.uk/centres/hailsham-leisure-centre/specialised-exercise-at-hailsham-leisure-centre/ Requires GP referral (<i>Due to Covid-19 classes not currently being delivered, but there is a plan to restart them</i>) Tel: 01323 846755 option 5
Macmillan Safefit	Exercise Macmillan SafeFit - is a free remote service for anyone in the UK with suspicion of or confirmed diagnosis of cancer. Our cancer exercise specialists offer you advice, support and resources to maintain and improve physical and mental well-being. You can refer yourself.	https://www.macmillan.org.uk/cancer-information-and-support/get-help/physical-help/safefit
NHS Exercise Advice and Videos	NHS Exercise advice and workout videos - Advice and home workout videos, including a cardio workout, and a strengthening workout.	https://www.nhs.uk/oneyou/for-your-body/move-more/home-workout-videos/
	Yoga (NHS) - Yoga can help with strength	https://www.nhs.uk/conditions/nhs-

Yoga (NHS)	and flexibility as well as keeping you active. It can also be relaxing. The NHS website has a 45-minute home yoga video for beginners at any fitness level.	fitness-studio/yoga-with-lj/
10. Support Groups		
Pink Ladies Hastings	<p>1066 Pink Ladies Hastings – is a Breast Cancer Support Group which meets at: St. Leonards Parish Church, Undercliff, St. Leonards, TN38 0YW.</p> <p>The service they offer is befriending, cancer information materials, counselling, home visiting and hospital visiting.</p> <p>Catchment area: East Sussex</p>	<p>http://www.1066pinkladies.org.uk/</p> <p>Find out more:</p> <p>Pat: 01424 220665 Pam: 01424 753152 Gloria 07711292822</p> <p>Email: info@1066pinkladies.org.uk</p>
Care for Carers East Sussex	<p>Care for the Carers - is an independent charity and the Carers Centre for East Sussex. Their team of staff and volunteers can provide free practical and emotional advice – face to face, by telephone, or online. They can put you in touch with other carers, and help you navigate the range of services available locally. They also run support groups, training and events across the county – whether you are interested in speaking up on important issues, or having some time out to relax or meet new people.</p>	<p>https://www.cftc.org.uk/</p> <p>Care for the Carers. Highlight House, 8 St. Leonards Road, Eastbourne, East Sussex, BN21 3UH.</p> <p>Call on: 01323 738390</p> <p>Text on: 07860 077300</p> <p>Email on: info@cftc.org.uk</p>
Cancer Care Map	<p>Cancer Care Map - Search the Cancer Care Map for cancer support services in your area: Shows local support groups, health and wellbeing support, emotional support and medical services in your area, after entering your post code.</p>	<p>https://www.cancercaremap.org/</p>
Black Women Rising	<p>The Black Women Rising cancer support project was set up in 2019 by award-winning community champion Leanne Pero after she struggled with the aftermath of her own battle with breast cancer at just 30 years old.</p> <p>In her quest to find the right services to aid her, Leanne soon realised that the NHS lacked cancer support packages for BAME cancer patients. Further investigation into the visibility of BAME cancer patients in the UK started to unravel that in most instances, the cancer stories of her community were being excluded from the UK's mainstream media outlets, magazines, daily tabloids and more damagingly from reputable annual cancer campaigns by brands and charities</p>	<p><u>CONTACT BLACK WOMEN RISING</u> <u>(blackwomenrisinguk.org)</u></p>

	failing miserably at diversifying their campaigns.	
Woman's Support Group	Facing Cancer Together- Women's Support Group - The group is for women no matter what stage of their cancer journey, as well as women who are caring for someone with cancer. Women do not need a referral to attend they are welcome to just come along. People often make a small tea donation if they wish.	http://www.facingcancertogetherheathfield.org.uk/ Tel. 07413 311382 Email: facingcancertogetherheathfield@gmail.com Address: State Hall (Kings Church) Station Road Heathfield East Sussex TN21 8LD
Support for Men with Breast Cancer	Support for Men with Breast Cancer - Breast Cancer Now 'Someone Like Me service'. For men who may feel isolated and do not know another man in the same situation. Provides someone to talk to.	https://breastcancernow.org/information-support/have-i-got-breast-cancer/breast-cancer-in-men
Macmillan Online Support	Macmillan On-line Community - The Macmillan Online Community is a free online place for people who are living with or who are affected by cancer to chat about the issues affecting them.	https://www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/online-community
Macmillan LGBT Lounge	Macmillan LGBT Lounge - The LGBT Lounge is a place for members of the LGBT+ community to share and discuss their experiences with cancer, with others who can understand what you're going through.	https://community.macmillan.org.uk/cancer_experiences/lgbt/

Sara Lee Trust	Sara Lee Trust - is a practical help and support group. The Sara Lee Trust offers support to people and their main carer/relative through complementary therapies, counselling and support events.	http://www.saraleetrust.org/ Natural Rhythms Group for patients on Tuesday mornings 10.30 - 12.30 Tel: 01424 445608 (for details). Sanctuary days once a month for patients 10 - 4. Find out more: Sarah Geall on 01424 445608 (Mon-Friday, 09.00 - 16.00) Email: saraleecentre@stmichaelshospice.com
11. Personal Health record		
Patient Knows Best Personal Health Record	Access your personal health record. Receive appointments letters and test results online and in the future it is hoped, you will also be able to share and communicate with your health team via Patient Knows Best (PKB).	https://patientsknowbest.com/patients-and-carers/ 0800 088 5827 or +44 1223 790708

Sources of information

Surrey and Sussex Cancer Alliance, Breast Nurse Consultant, Clinical Nurse Specialists, Consultants

<https://www.england.nhs.uk/south-east/cancer-alliances/surrey-and-sussex-cancer-alliance/>

Web site addresses.

Important information

This patient information is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the patient experience team on 0300 131 4784 or esh-tr.patientexperience@nhs.net

Hand hygiene

We are committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

If you require any of our leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department on 0300 131 4434 or esh-tr.AccessibleInformation@nhs.net

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

Reference

The following clinicians have been consulted and agreed this patient information:
Enter names and Job titles (at least one from each site if appropriate)

The Clinical Specialty/Unit that have agreed this patient information leaflet:
Enter name here, if appropriate

Next review date: October 2025
Responsible clinician/author: Kelly Smith/Isabelle O'Donnell

© East Sussex Healthcare NHS Trust – www.esht.nhs.uk