



*Living better with advanced breast cancer*

A supportive, self-management website for women  
living with secondary breast cancer

## The LIBERATE User Guide

Version 1.0, December 2019

### Contact details

The LIBERATE Research Team

Kathleen Kane, PhD student

Email: [um08k2k@leeds.ac.uk](mailto:um08k2k@leeds.ac.uk)

Telephone: 0113 20 67580

Section of Patient Centred Outcomes Research, level 6 Bexley Wing,

St James's University Hospital, Leeds LS9 7TF

## Welcome to the LIBERATE User Guide

Thank you for agreeing to take part in the LIBERATE study.

This guide provides you with information on how to access the various different features of the LIBERATE website, which has been designed to meet the needs of women living with secondary breast cancer. It is made up of five key areas:

- **Holistic health information:** evidence-based information on lots of different health and lifestyle topics relevant to secondary breast cancer, brought together in one place.
- **Virtual 'waiting room' of case studies:** a wide variety of cases based on the real-life experiences of secondary breast cancer patients, promoting learning through shared experience.
- **Support for others:** a range of information for family, friends, loved ones, colleagues and others affected by the diagnosis of secondary breast cancer, gathered in one place.
- **Signposting support:** a list of websites, resources and support services for women and families coping with secondary breast cancer, alongside guidance on how to search for appropriate support using the internet.
- **Symptom monitoring:** link to an online questionnaire system, developed within our research group, where patients can report on a range of symptoms and issues and receive tailored self-management advice.

This guide will take you through, step-by-step, how to find and move through these different areas, as well as how to access and complete symptom monitoring questionnaires.

### Step 1: Finding the LIBERATE website

#### Step 2: Exploring the LIBERATE website

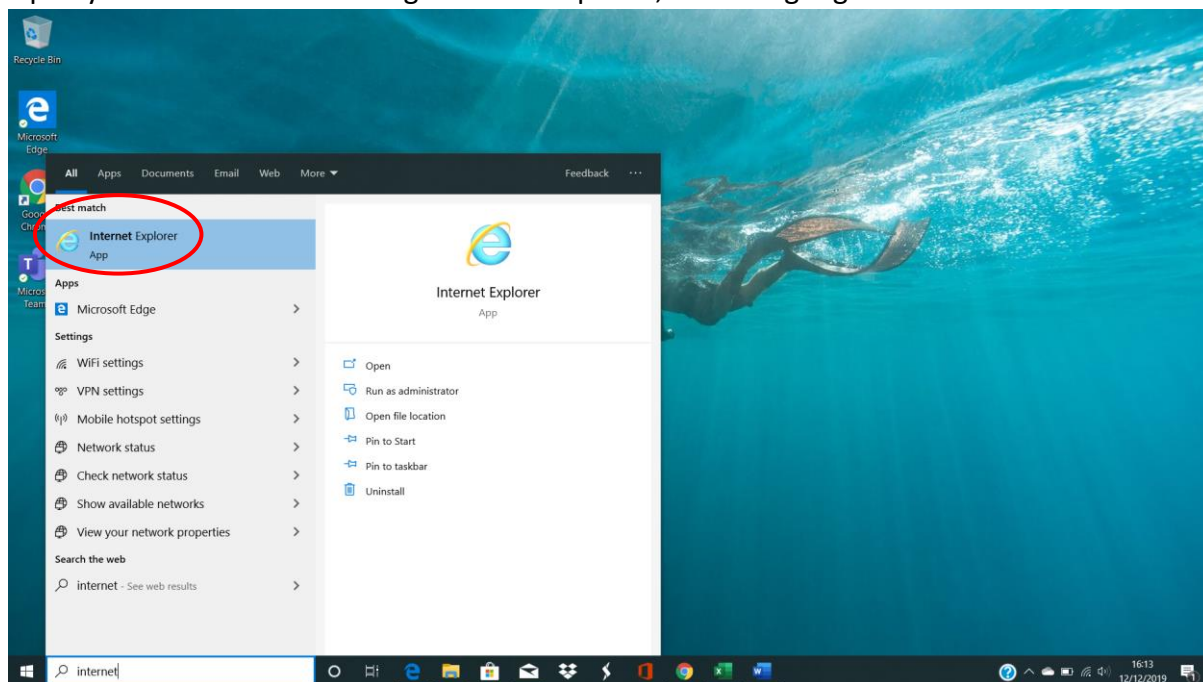
- The welcome page
- Main menu bar & drop-down menus
- Links to other pages & websites
- Returning to the top of the page
- Using the search function
- Sources of information
- Further information & page overviews
- Downloading case studies

#### Step 3: Symptom monitoring

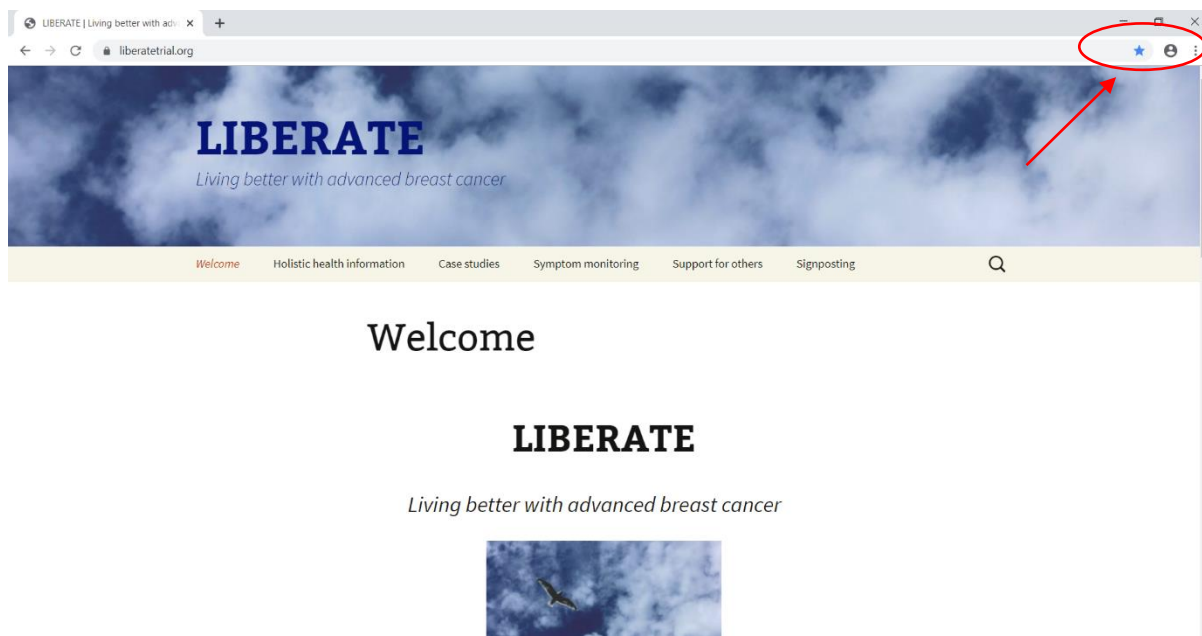
- How to find the symptom monitoring questionnaire
- Logging in to the QTool website & completing the questionnaire
- Self-management advice
- Making sense of the graphs
- Reviewing results

## Step 1: Finding the LIBERATE website

1. Open your internet browser e.g. internet explorer, safari or google chrome.



2. Type in [www.liberatetrial.org](http://www.liberatetrial.org)
3. By clicking on the star in the top right-hand corner, you can add this page to your 'favourites' so it will be easier to get to when you next come to use it.



You do not need a username or password to access the LIBERATE website. However, we ask that you do not share this website with others who are not taking part in the study, or who may be on the waiting list to take part in the study at a later date, as this may affect our results.

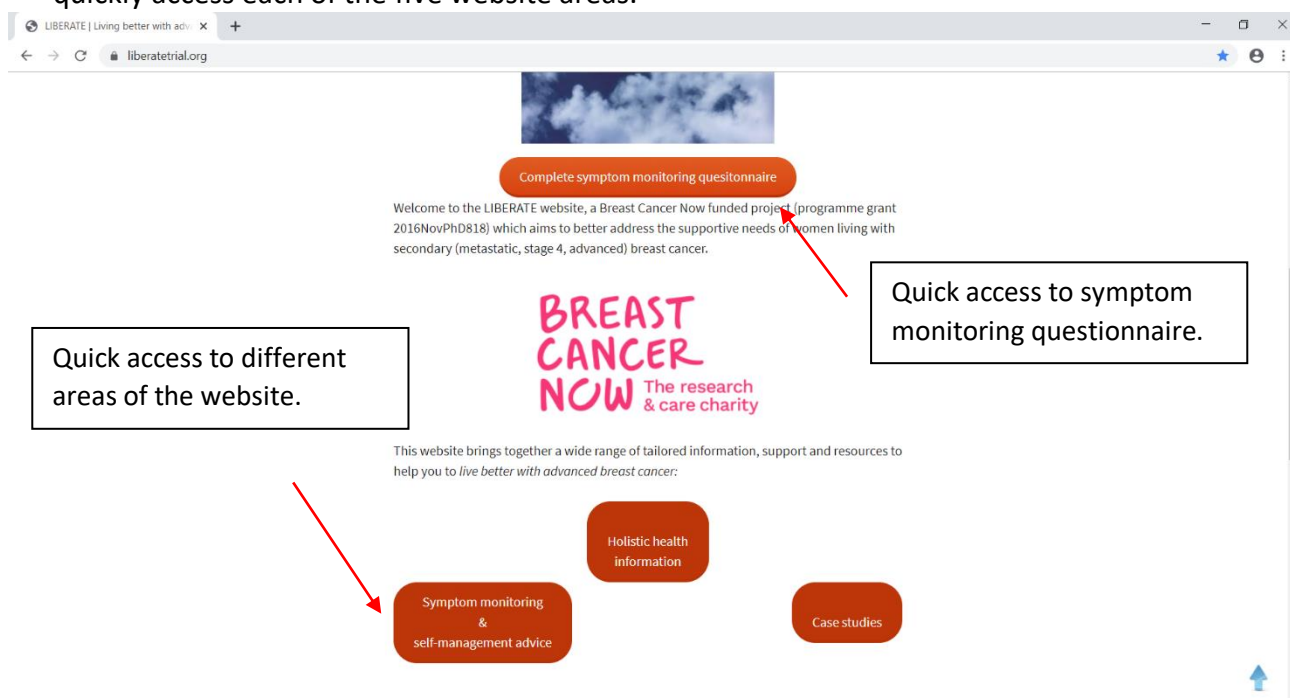
## Step 2: Exploring the LIBERATE website

### The welcome page

The first page you will come across is the welcome page. This explains a little about the study and provides contact details for the research team.

There is also a link you can follow (by clicking the orange button) to quickly access a symptom monitoring questionnaire. For further details on how to complete a symptom monitoring questionnaire, *please see page 11 of this guide*.

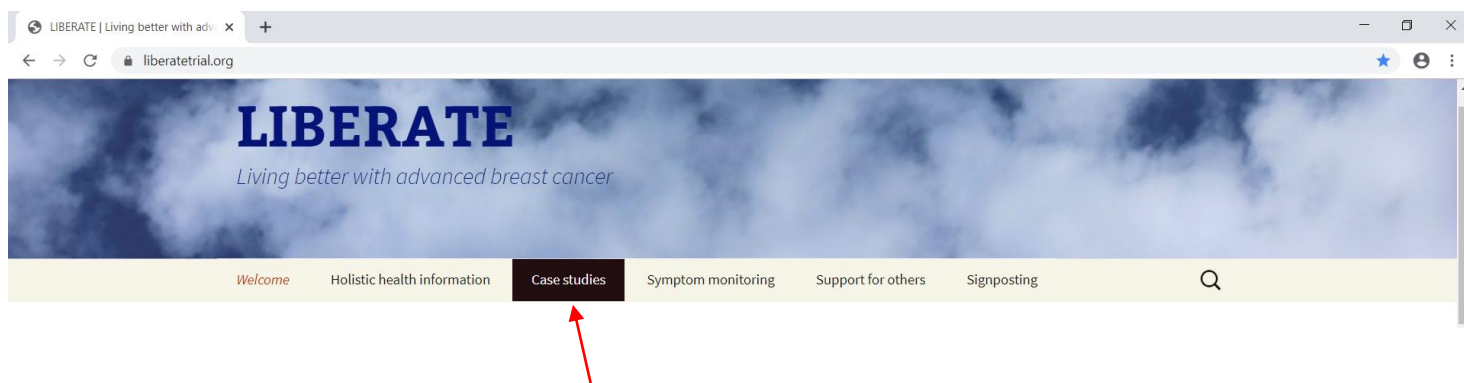
If you scroll down, you will find a series of orange buttons. By clicking on these, you can quickly access each of the five website areas.



### The main menu

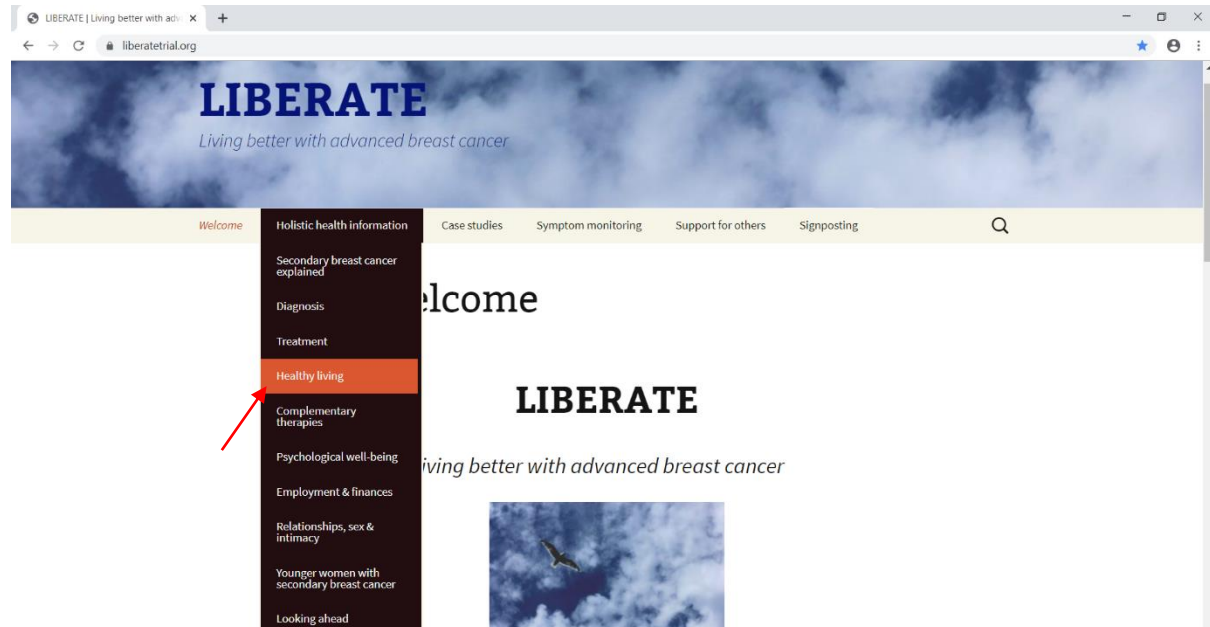
You can also find each section of the LIBERATE website across the main menu bar at the top of the page, just below the clouds.

By clicking directly on each section (e.g. 'Case studies'), you will be taken to this page.

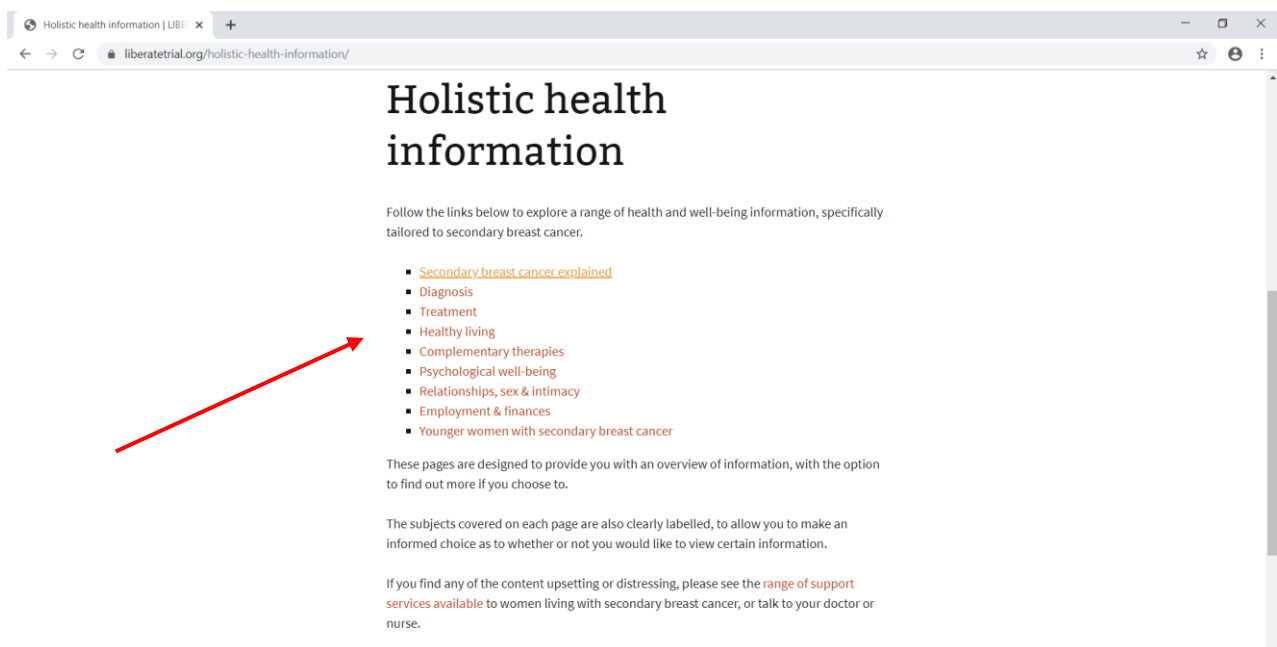


## Drop-down menus

If you hover over the main menu bar, you will see that some of the sections also have a drop-down menu. This is where the area contains multiple pages or sections. You can get to each section by clicking on it in the drop-down menu.



Alternatively, there are links listed on the main page of each area.

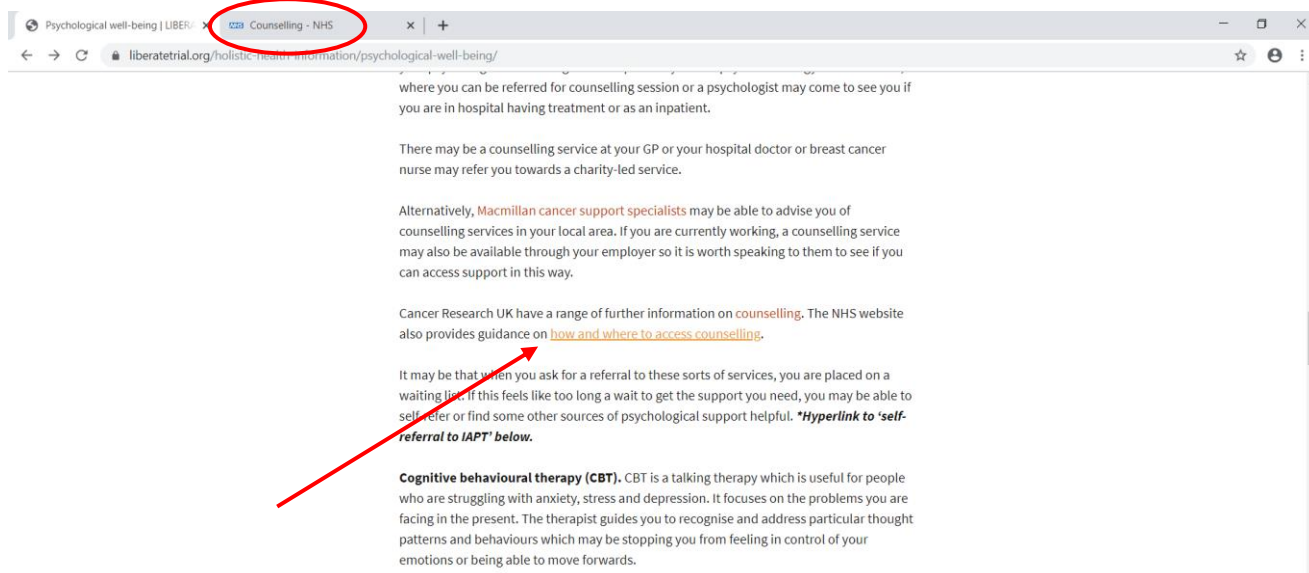




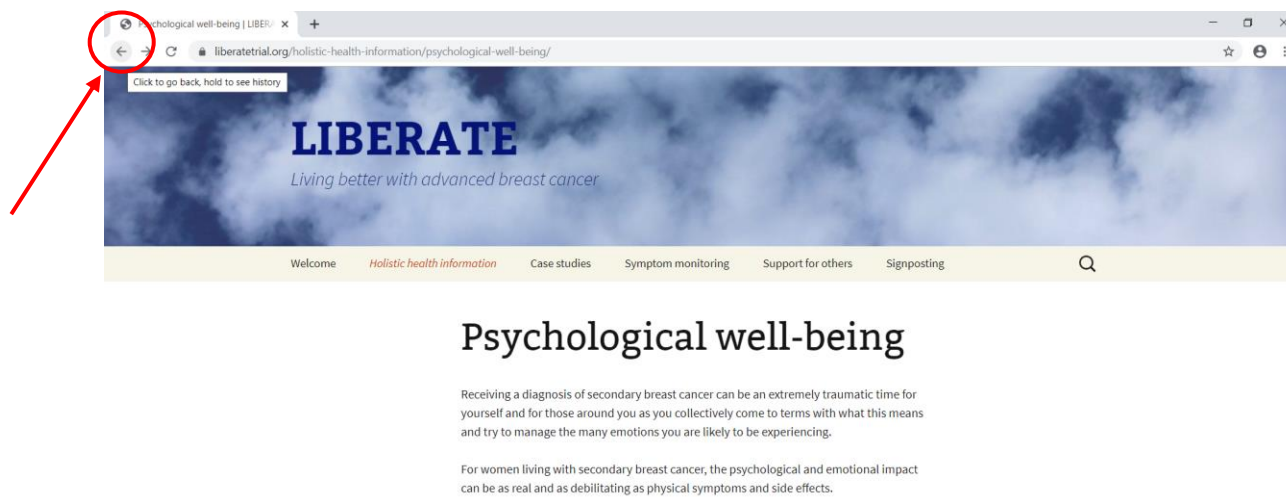
## Links to other pages and websites

Our website contains lots of links to guide you towards useful sources of information and support. If you notice any text underlined and in orange, this means that by clicking on it, you will automatically be taken to another website or another section of the LIBERATE website.

For external websites (i.e. a website which is not the LIBERATE website), these will open in a separate tab, allowing you to continue looking at the page you are on.

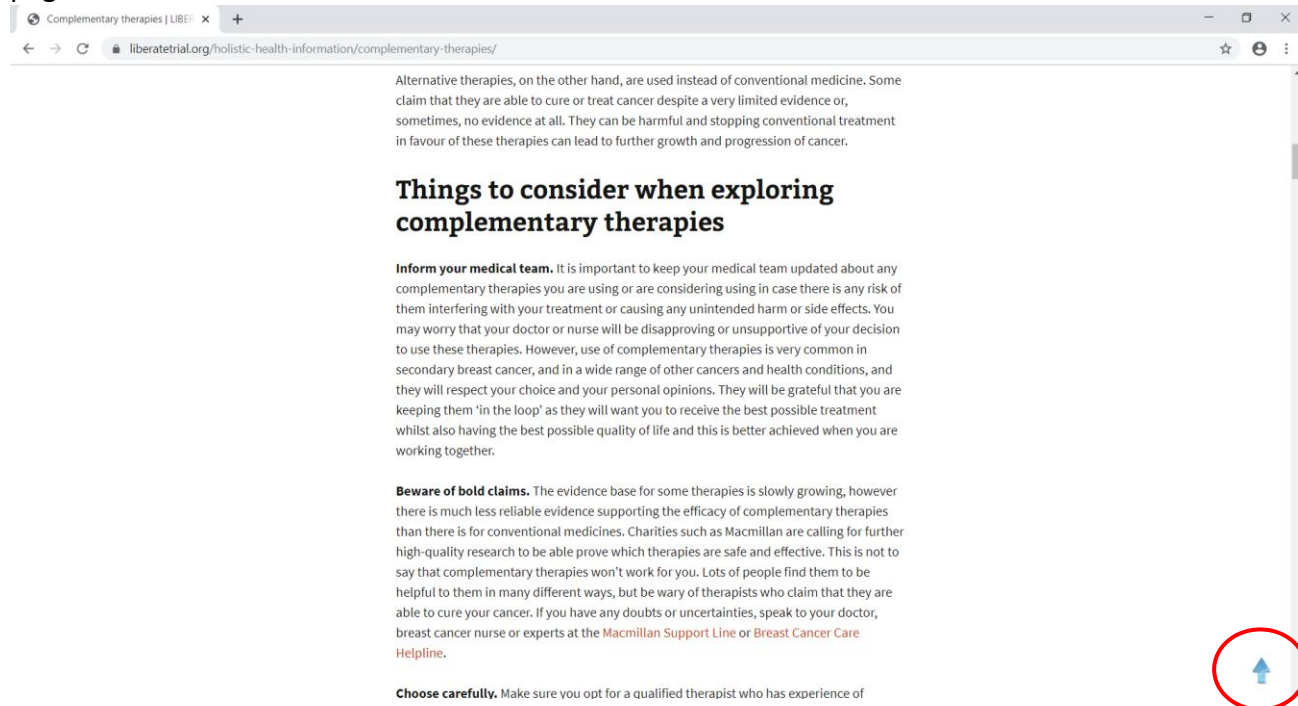


For different sections of the LIBERATE website, you will be taken away from the page you are currently viewing. You can always come back to it by simply clicking the 'back' button.



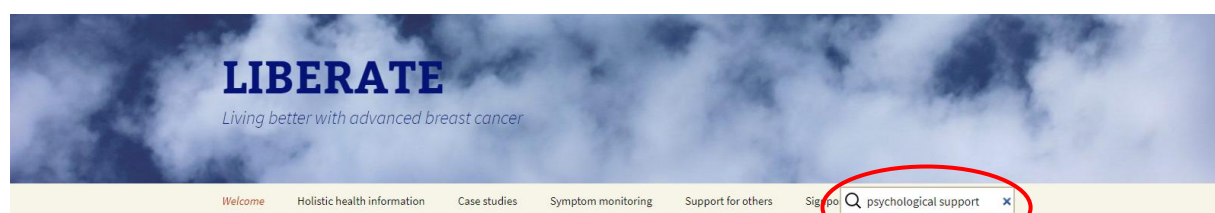
## Getting back to the top of the page

Some of the pages contain lots of information. To allow you to scroll quickly back to the top of the page, so that you can access the menu bar again, you can simply click the little blue arrow which is pointing upwards and can be found in the bottom right hand corner of every page.



## Using the search function

The search function allows you to search the entire website for key words or phrases. Simply click the magnifying glass in the top right-hand corner of any page, type in what you are looking for and press the 'enter' or 'return' key on your keyboard.

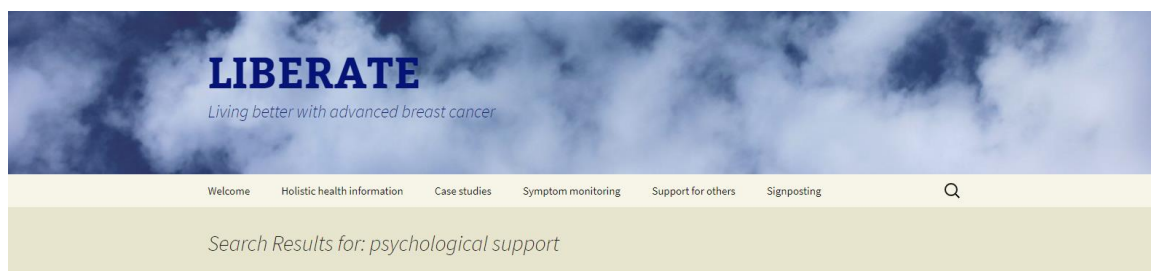


Welcome

**LIBERATE**

Living better with advanced breast cancer

You will then see a list of results containing the key word or phrase and will be able to click on these for further information.



## Psychological well-being

Receiving a diagnosis of secondary breast cancer can be an extremely traumatic time for yourself and for those around you as you collectively come to terms with what this means and try to manage the many emotions you are likely to be experiencing. For women living with secondary breast cancer, the psychological and emotional impact ... [Continue reading](#) →

## Support for others

This section is designed to provide information and support to those affected by the cancer diagnosis of a loved one, friend or colleague. If you are living with a diagnosis of secondary breast cancer and feel that your family and friends may need some support, please direct

## Sources of information

All of the information on the LIBERATE website has been gathered from reliable and evidence-based sources. You can see where the information on a particular page has come from by seeing 'references' and 'sources' at the bottom of each page or section.

Overall, continued research is needed for us to better understand this link.

Harvard University School of Public Health's website has range of further information on the evidence behind soy, health and disease.

### References

1. Sacks FM, Lichtenstein A, Van Horn L, Harris W, Kris-Etherton P, Winston M. **Soy protein, isoflavones, and cardiovascular health: an American Heart Association Science Advisory for professionals from the Nutrition Committee.** *Circulation*. 2006 Feb 21;113(7):1034-44.
2. Trock BJ, Hilakivi-Clarke L, Clarke R. **Meta-analysis of soy intake and breast cancer risk.** *Journal of the National Cancer Institute*. 2006 Apr 5;98(7):459-71.
3. Michels KB, Mohlajee AP, Roset-Bahmanyar E, Beehler GP, Moysich KB. **Diet and breast cancer: a review of the prospective observational studies.** *Cancer: Interdisciplinary International Journal of the American Cancer Society*. 2007 Jun 15;109:2712-49.
4. Linos E, Willett WC. **Diet and breast cancer risk reduction.** *Journal of the National Comprehensive Cancer Network*. 2007 Sep 1;5(8):809-16.

### Other sources

- Cancer Research UK: Food controversies – Soy
- Harvard T.H. Chan School of Public Health: The Nutrition Source – Straight Talk About Soy

## The dairy-free diet

The dairy food group is made up of milk and other products which are made (derived) from milk, including cheeses and yoghurt.

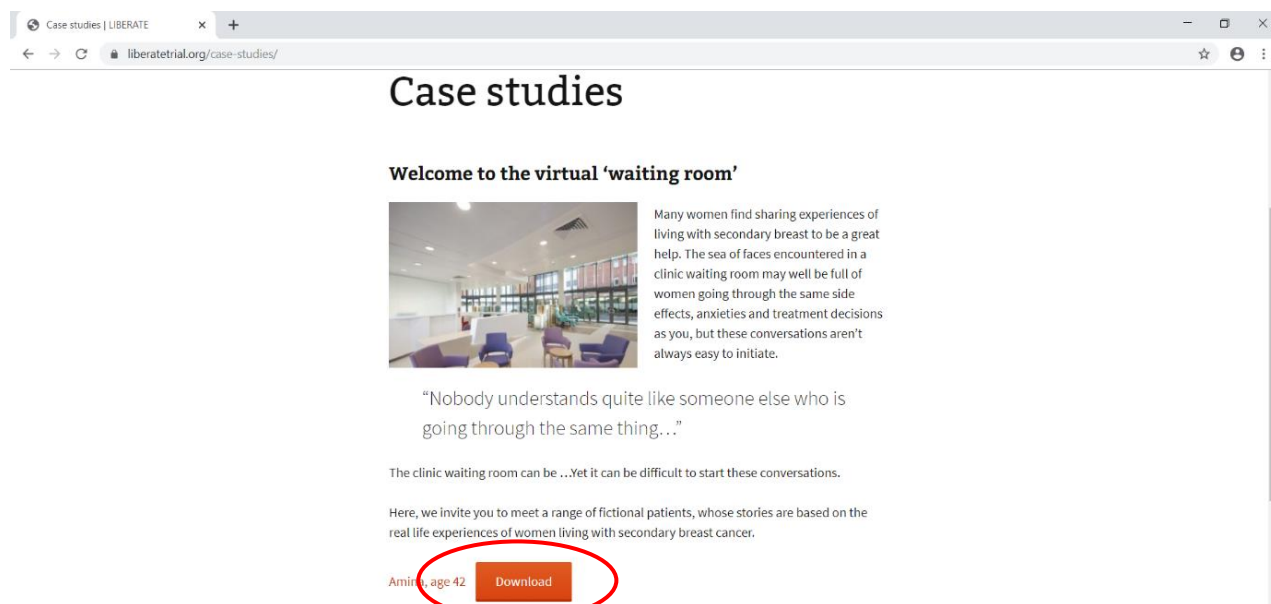
Dairy is an essential aspect of a healthy, balanced diet, since these foods provide us with key vitamins and nutrients, including vitamin B2 and B12, iodine, calcium and protein. Calcium is very important for forming and maintaining





## Downloading case studies

Within the 'Case studies' area, there are a wide range of fictional patients' stories which have been written based on the real-life experiences of women living with secondary breast cancer. There is a short description of each patient next to an orange 'download' button. Simply click on this button and the case study will be downloaded as a word document for you to read in full.



## Further information

Across the website, there are a number of areas where you can choose to access further information on particular topics.

- Whether you have been treated with chemotherapy previously. If so, which drug and how well it worked,
- Your general health,
- Your own personal priorities (e.g. whether you would prefer tablets, whether hair loss is a major concern for you),
- Side-effects you have experienced in the past and how manageable they were for you.

### What to expect

Before starting your chemotherapy, your doctor or nurse will provide you with a contact number to use at any time, day or night, if you are feeling unwell during treatment. They will also explain any side effects that you might have and how they can be managed. This can be a lot to take in at once.

Depending on the drug, chemotherapy may either be given as tablets to swallow or as a 'drip' through a needle in your vein.

If you have your chemotherapy delivered intravenously (via a needle in the vein),

[Further information](#)

### Side effects

Because chemotherapy drugs also affect the body's normal cells, you may experience a range of side effects. These can differ depending on the drug you are treated with but common side-effects include;

- Nausea and sickness
- Hair loss
- Sore mouth
- Soreness of the skin on hands and feet
- Pins & needles and pains in the hands and feet
- Skin & nail changes
- Forgetfulness and difficulty concentrating ('chemo brain')

### Hormone therapy

Unless you click on ‘further information’, the information remains hidden, giving you the option of whether or not you see more detail. You may choose to come back to certain information at another time.

## Page overviews

Most of the pages on the LIBERATE website also begin with a ‘page overview’. This allows you to find out what sort of information will be covered before you continue reading.

## Employment & finances

You may find that, at this point in time, your ability to work is only affected in the short-term, for example when attending hospital for treatment, in the days immediately after a treatment or at times when side-effects are particularly difficult to manage.

On the other hand, you may feel that you are physically less able to cope with the demands of your job anymore. Psychologically, some women also experience a shift in their priorities and perspective, feeling that their secondary breast cancer diagnosis has signalled a need for them to spend more time with loved ones and doing what they want to do. If you are financially able to do so, this may mean giving up work altogether or considering part-time working. Alternatively, you may decide a change of job would better suit your needs.

The stress and anxiety of making decisions about work and managing your finances can be a lot to cope with on top of the worries and struggles brought by a diagnosis of secondary breast cancer. Whether family, friends, health professionals or via an online support group or discussion board, sharing your worries or asking for the advice of others can help you to feel less alone and may allow you to see things from a different perspective or to consider other options and solutions.



Here, we provide a range of guidance and direct you towards lots of sources of information and advice to support you in making decisions about your work and finances.

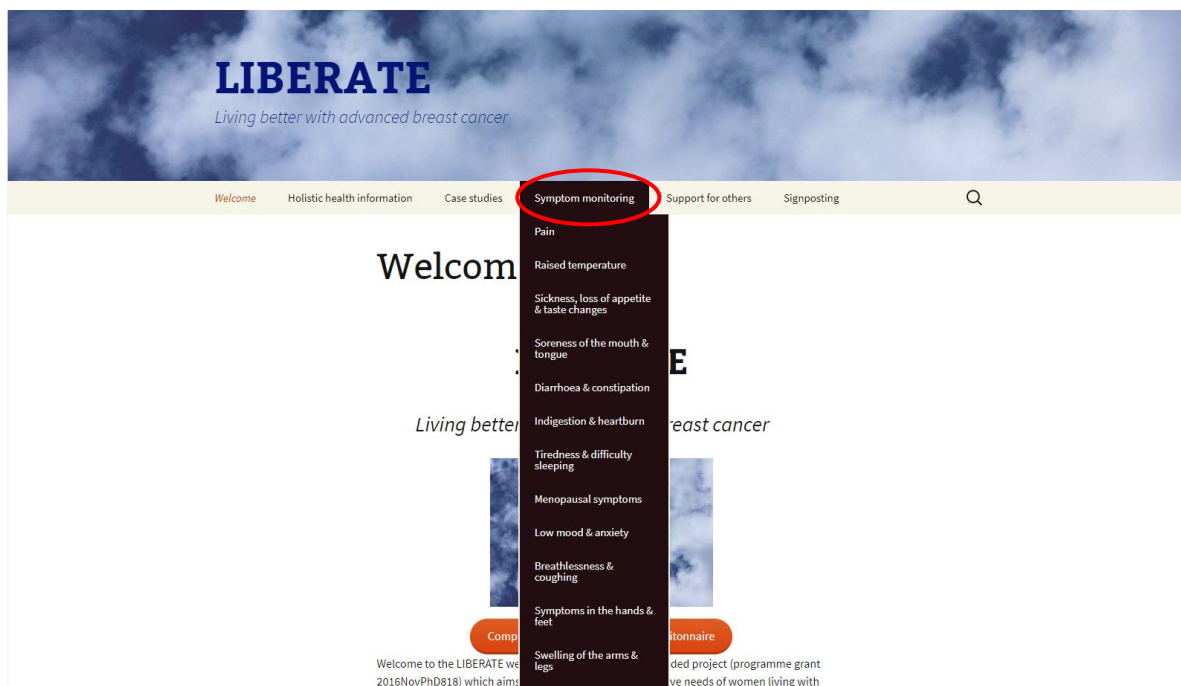
- [Support to continue working](#)
- [Support for the self-employed](#)
- [Support when considering whether to continue working](#)
- [Support when you no longer feel able to work](#)
- [Financial advice](#)
- [Pensions advice](#)
- [Debt management advice](#)
- [Sources of financial support](#)

## Step 3: Symptom monitoring

### Finding the symptom monitoring questionnaire & logging in

As well as being on the welcome page, the link to complete a symptom monitoring questionnaire can be found in the **'Symptom monitoring'** area of the website.

1. Click on the 'Symptom monitoring' section on the main menu along the top of the screen. You will be directed to the main page, where you will find an orange button **'Complete symptom monitoring questionnaire'**.



2. This button can also be found at the top of all of the self-management advice pages within the 'Symptom monitoring' section.



## Diarrhoea & constipation

Living with and being treated for secondary breast cancer can cause a range of issues with your bowel motions, either increasing or reducing their frequency. This may be a short-term symptom or side-effect, or may be something you experience in the longer term.

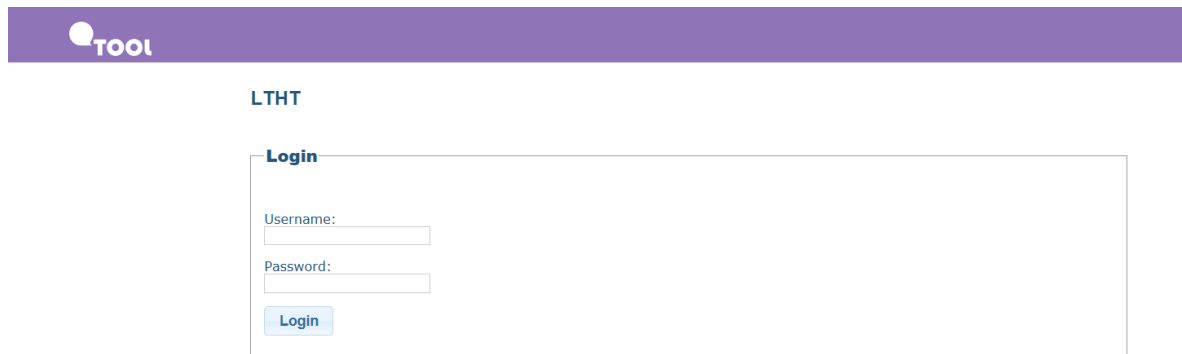
- Diarrhoea
- Tips for coping with diarrhoea
- Overflow diarrhoea
- Constipation
- Tips for coping with constipation

### Diarrhoea

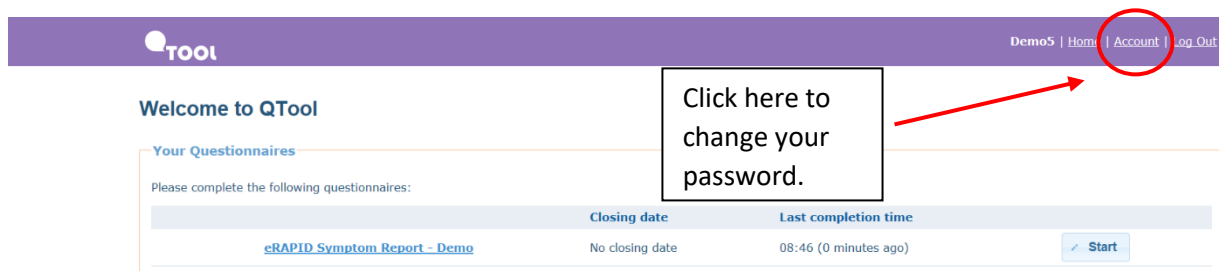
[Complete symptom monitoring questionnaire](#)

### Completing a symptom monitoring questionnaire

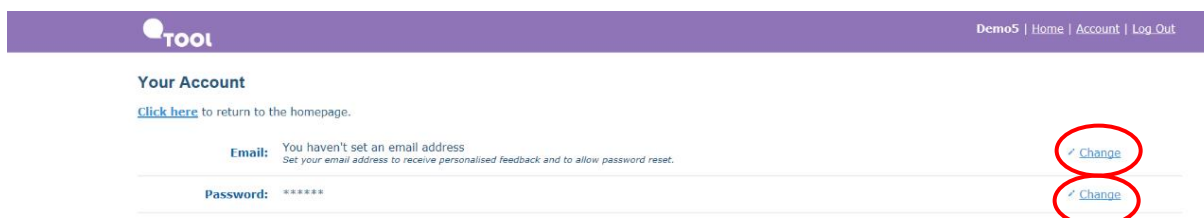
- After clicking the orange button, you will be directed to the QTool website. Here, you will need to enter the **log in details** which you have been provided with (if you have forgotten or lost your username or password, please contact the research team via the contact details on the front of this guide).



- You will be taken to a screen which is similar to the one below. To change your password to something more memorable, you can click on the 'account' tab on the top right-hand corner.



- You will have the option of creating a new password and adding your email address. This means that, if you forget your password again, you can request for it to be reset and instructions will be emailed to you automatically.



- Once you have logged in, the title of your questionnaire will appear (e.g. 'LIBERATE RCT hormone/targeted therapy') with a **'Start' button** to the right-hand side. Click the start button to begin.

The screenshot shows the QTool interface. At the top, there's a purple header with 'TOOL' on the left and 'Demo5 | Home | Account | Log Out' on the right. Below the header, it says 'Welcome to QTool'. Under 'Your Questionnaires', there's a table with columns 'Closing date' and 'Last completion time'. The first row shows 'eRAPID Symptom Report - Demo' with 'No closing date' and '08:46 (1 hour ago)'. To the right of this row is a blue button labeled 'Start' with a checkmark icon, which is circled in red. A red arrow points from a callout box that says 'Click here to begin.' to the 'Start' button. Below the table, there's a section for 'Your Studies' showing 'eRAPID Demo'. Under 'Your Previous Responses', there's a link 'Click here to view detailed responses and feedback.'

- For each question, click on the response which best suits you.
- After each question, click **'Next'** on the bottom right-hand side of the screen.

**During the past week:**

Have you had any pain or discomfort anywhere in your body?

- ☐ No.
- ☒ I had mild pain or discomfort.
- ☐ I had moderate pain or discomfort and I was not able to do some of the things I normally do (e.g. household chores, shopping).
- ☐ I had severe pain or discomfort and I was not able to care for myself (e.g. getting out of bed, bathing, dressing).

**Next Page**

- If you report a severe symptom, you may be asked whether this is current problem, or whether it has resolved.

**During the past week:**

Have you had pain or discomfort anywhere on your body?

- ☐ No
- ☐ I had mild pain or discomfort
- ☐ I had moderate pain or discomfort and I was not able to do some of the things I normally do (e.g. household chores, shopping)
- ☒ I had severe pain or discomfort and I was not able to care for myself (e.g. getting out of bed, bathing, dressing)

Please tell us where the pain is

Is this a current problem or has it now improved?

- ☐ This is a current problem for me
- ☐ I have experienced this problem in the last 7 days but it has now improved

**Next page**



10. If you report a symptom which requires immediate medical attention, you will be advised to contact your hospital to seek advice (a message will appear along the bottom of the screen in red).

If you feel able to at that time, we ask you to complete the rest of the questionnaire as this information will be useful for your medical team. Otherwise, please contact your hospital immediately.

**During the past week:**

Have you lacked appetite or lost interest in food?

- ☐ No
- ☐ I have lacked appetite but I was able to eat and drink the SAME AMOUNT and type of food as usual
- ☐ I have lacked appetite and I ate or drank LESS THAN usual or I have been taking supplement drinks
- ☒ I have lacked appetite and I was not able to eat or drink

You have indicated a serious problem in this area. We recommend that you contact the hospital now to discuss your symptoms with the medical team (St James's University Hospital 0113 243 3144 and ask for the Oncology Patient Enquiries Bleep Holder). Before you contact the hospital and if you feel able, please complete the remaining questions.

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[Next page](#)

11. Near the end of the questionnaire, there is the opportunity to report any further symptoms which haven't already been covered.

You will be able to select symptoms from a list and will be asked to describe how severe the symptoms you experienced were.

**During the past week:**

Have you had other side effects, not listed here?

- ☐ No
- ☒ Yes

Please tell us about **up to three** of these below.

1)

Shortness of breath

What was the severity of your shortness of breath?

- ☐ I have been short of breath but only when exerting myself (e.g. climbing stairs)
- ☐ I have been short of breath when walking around the house and I was not able to do some of the things I normally do (e.g. household chores, shopping)
- ☐ I have been short of breath at rest and I was not able to care for myself (e.g. getting out of bed, bathing, dressing)

2)

3)

[Previous page](#)

[Next page](#)

12. At the end of the questionnaire, you will be shown a summary list of the all of the questions and your answers to each one. At this point, you will have the option of reviewing and changing any of your answers by clicking on the **'Amend'** button.

Question	Response	
<b>During the past week:</b> Have you had pain or discomfort anywhere on your body?	No	<a href="#">Amend</a>
<b>During the past week:</b> Have you felt tired, fatigued or lacked energy?	No	<a href="#">Amend</a>
<b>During the past week:</b> Have you lacked appetite or lost interest in food?	I have lacked appetite and I was not able to eat or drink	<a href="#">Amend</a>
Is this a current problem or has it now improved?	This is a current problem for me	<a href="#">Amend</a>
<b>During the past week:</b> Have you had other side effects, not listed here?	No	<a href="#">Amend</a>

[Previous page](#)

It is worth noting, if you do go back and change a response, you will then have to complete the rest of the questionnaire from that question onwards again. However, your previous answers will still be selected so you will simply need to click 'Next' after each question to get through to the end again.

13. When you reach the end, please click the **'finish'** button to submit your answers.

### ***Symptom self-management advice***

1. When all of the questions in your questionnaire have been completed, the system will immediately provide you with tailored advice for the symptoms which you have reported to be a problem.

For serious symptoms, you will again be advised to contact your hospital immediately to speak to a member of your medical team about the problem. For example:

Please read the advice below based on your responses

You have indicated that you have experienced some symptoms with:

- Lack of appetite

We recommend that you contact the hospital now to discuss your symptoms with the medical team (St James's University Hospital 0113 243 3144 and ask for the Oncology Patient Enquiries Bleep Holder).

You can also find information and advice about managing your symptoms [here](#).

[Previous page](#)

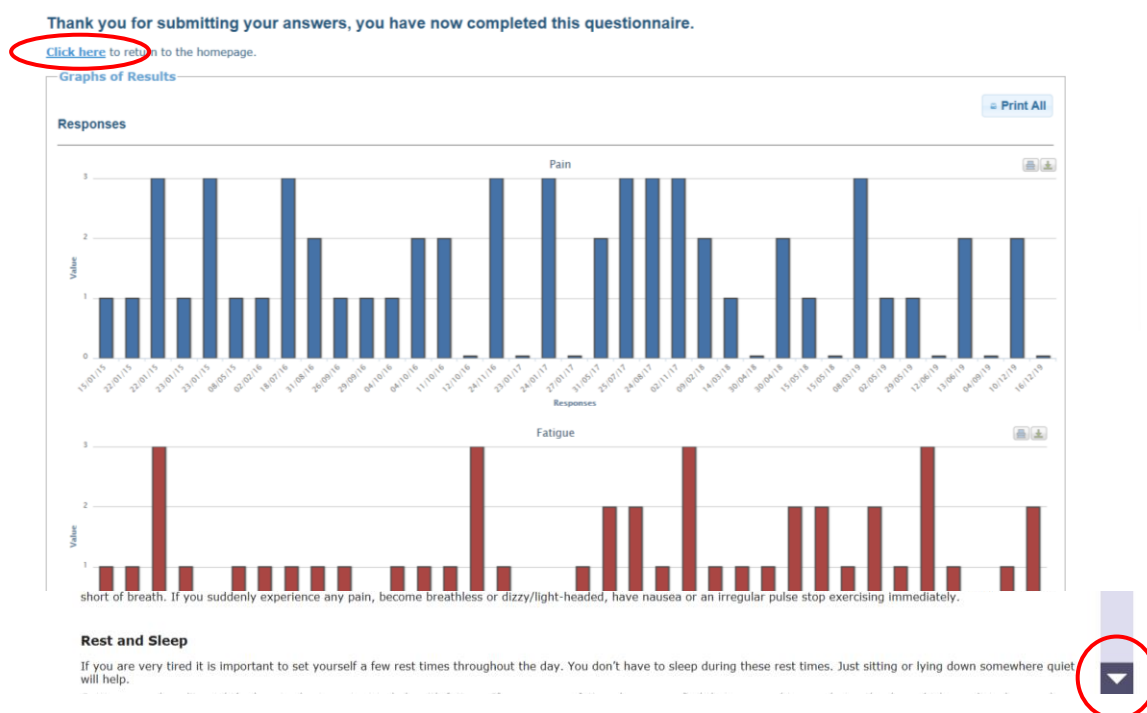
[Finish](#)

For less serious symptoms, the system will provide you with a summary of tailored advice to help you to manage these issues, **directing you to the advice in full on the LIBERATE website**. If a number of less serious symptoms are reported, advice for all of these may not be provided at the end of the questionnaire. However, self-management advice for all symptoms is available on the LIBERATE website in the 'Symptom-monitoring' section of the LIBERATE website (*please see page 18 of this guide*).

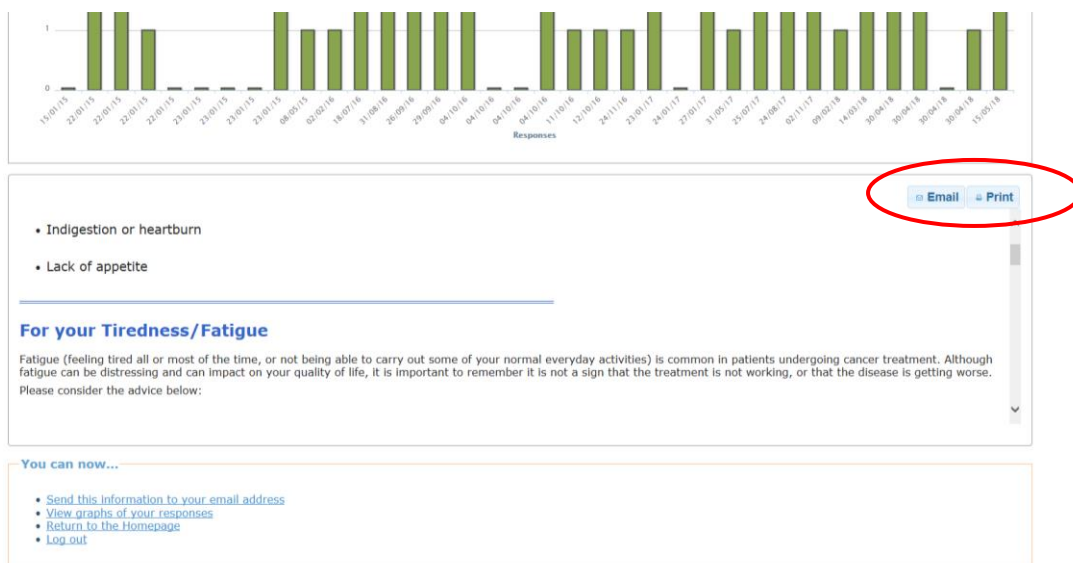
2. You will be able to scroll down to the bottom of the page (using the arrow on the left-hand side, circled in red above) and click '**finish**'.

You will then be taken to a page which thanks you for submitting your responses.

A summary of some of your questionnaire responses will be displayed in a graph. For guidance on making sense of these graphs, *please see page 19 of this guide*.



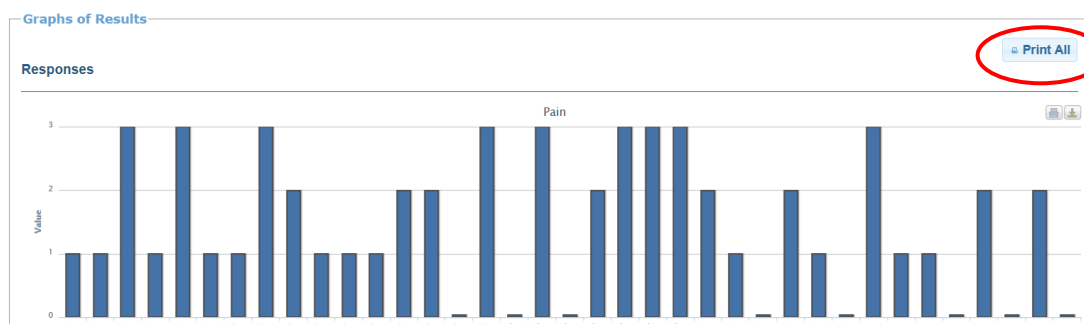
4. If you scroll down the page, you will see that, underneath these graphs, your self-management advice and feedback, tailored to your questionnaire responses, is displayed again. Here, there is the option to **email the advice to yourself** or to **print it off**.



If you would also like to print off the graphs of your results, you can scroll back up to the top of the page and click on the '**Print all**' button which can be found at the top right-hand side.

Thank you for submitting your answers, you have now completed this questionnaire.

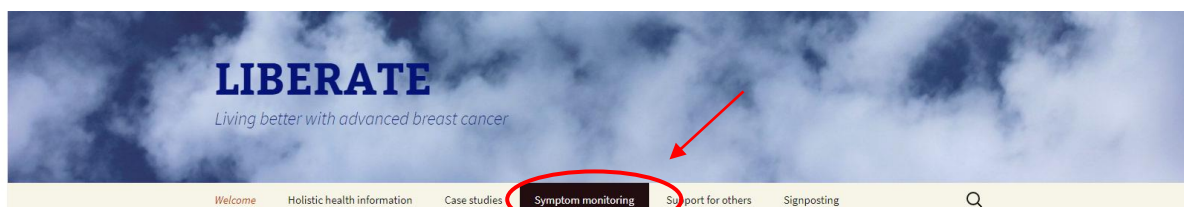
[Click here](#) to return to the homepage.



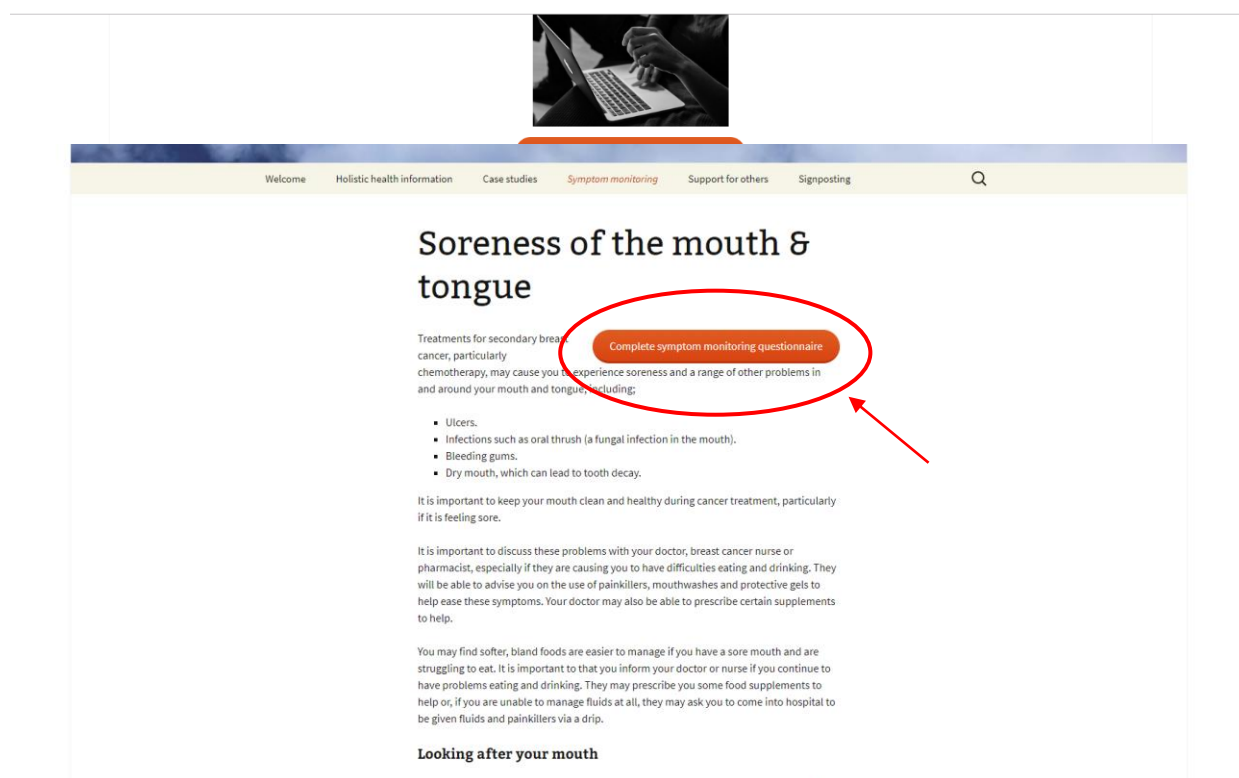
### Further self-management advice

A whole range of symptom and side-effect self-management information and advice is also available in the '**Symptom monitoring**' section of the LIBERATE website.

1. To access this, click on the 'Symptom monitoring' section on the main menu along the top of the screen.



2. Scroll down and you will see a list of symptoms and side effects. By clicking on each of these, you will be directed to a page of relevant information and advice.



3. If at any point, when reading the self-management advice, you wish to complete a symptom monitoring questionnaire, simply click on the orange button 'complete symptom monitoring questionnaire' which can be found at the top of every page.

4. Where relevant, there may be links to other sections of the website, for example 'Psychological well-being' or 'Complementary therapies'. By clicking on any orange, you will be taken directly to this section.



- Try to keep your bedroom as a space for sleeping. If your bedroom also doubles up as an office or a place to watch TV, this can make it harder to establish a bedtime and sleeping routine.

**Be patient with yourself.** It may take a few weeks after making these changes for you to notice a difference in your sleeping.

If you find that you are still struggling to sleep, speak to your specialist nurse/cancer doctor, who may be able to suggest some treatment to help if this is appropriate to your situation.

#### Treatment

- Your doctor may decide to prescribe you a short course of sleeping tablets, to help you to get back into a sleeping routine. If you are prescribed sleeping tablets, it is important that you take them as directed and do not exceed the maximum dose. Whilst these can be helpful in the short term, if taken over a longer period time, sleeping tablets can disrupt the quality and pattern of your sleeping.
- It may also help to review the medications you are already taking with your doctor, since some drugs are known to cause difficulty sleeping.

#### Other therapies

Some people find that therapies or practices which promote relaxation, such as yoga, mindfulness and meditation can help to improve their sleep. Talking therapies such as CBT (Cognitive Behavioural Therapy) or counselling can also help your sleeping by encouraging you to consider your thinking and behaviour.

Please see our sections on [Complementary therapies](#) and [Psychological well-being](#) to find out more.

Breast Cancer Care have shared some [expert tips](#) for improving your sleep

NHS choices also have a [podcast on sleeping problems](#) which you may find useful.

Sources

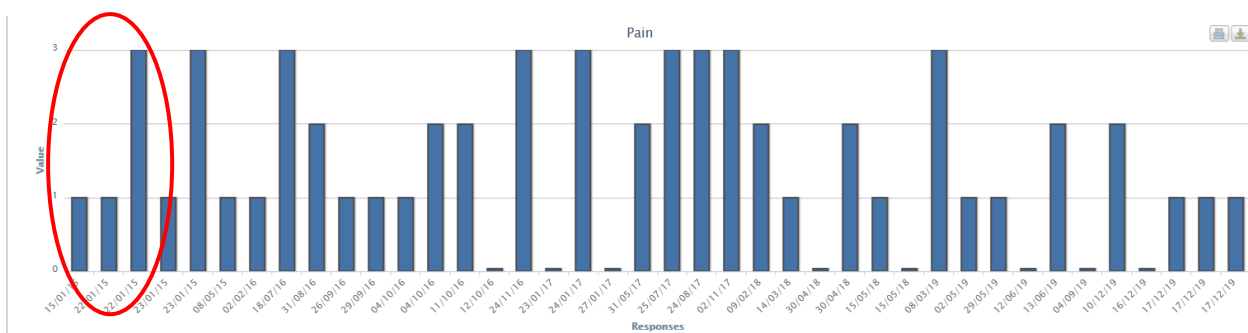
Links to other pages on  
the LIBERATE website.

## Making sense of the graphs

Some of the symptoms which you report will be displayed as graphs. Each of these symptoms will have their own graph.

The height of the bar represents the severity of the symptom.

The **higher** the bar, the **more severe** the symptom.



For example, the three bars circled in red above highlight an increase in symptom severity from the first questionnaire completion to the third.

Each time you complete a questionnaire and report the symptom, it will be shown as another bar on the graph. This allows you to monitor some of your symptoms visually and to see whether they change over time.

## Reviewing your results

If you scroll down to the bottom of the page, underneath the graphs, you will see a number of options.

**TOOL**

Demo5 | [Home](#) | [Account](#) | [Log Out](#)

Painkillers suitable for mild pain include:

**Paracetamol (click here to expand)**

It is very important that you do not take more than 8 normal strength paracetamol tablets (500mg each) in 24 hours. Doses of paracetamol must be at least 4 hours apart.

Caution:

- Do not take paracetamol if you are allergic to paracetamol;
- Many over the counter medicines such as cough, cold and flu remedies and other types of painkiller (such as co-codamol and co-dydramol) also contain paracetamol. If you are already taking paracetamol, do not take any other medication that contains paracetamol.

**Ibuprofen (click here to expand)**

It is very important that you do not take more than 6 normal strength ibuprofen tablets (200mg each) in 24 hours. Doses of ibuprofen must be at least 4 hours apart.

Caution:

**You can now...**

- [Send this information to your email address](#)
- [View graphs of your responses](#)
- [Return to the Homepage](#)
- [Log out](#)

To review previous responses to your questionnaires, and the results and feedback which you received:

1. Click on 'Return to Homepage'

**TOOL**

Demo5 | [Home](#) | [Account](#) | [Log Out](#)

**Welcome to QTool**

**Your Questionnaires**

Please complete the following questionnaires:

	Closing date	Last completion time	
<a href="#">eRAPID Symptom Report - Demo</a>	No closing date	11:11 (1 hour ago)	<a href="#">Start</a>

**Your Studies**


**eRAPID Demo**

**Your Previous Responses**

[Click here](#) to view detailed responses and feedback.

2. Next, 'click here'.

All of your previous responses will be displayed in a list, with the date and time of completion.


Demo5 | Home | Account | Log Out

**Previous Responses for eRAPID Demo**

[Click here](#) to return to the homepage.

**Previous Responses**

Your responses to previous questionnaires:

▼ **eRAPID Symptom Report - Demo**

You completed the questionnaire on the following occasions. Select a date to view your detailed responses and feedback that you received:

- [14:21 \(9 minutes ago\)](#)
- [13:31 \(59 minutes ago\)](#)
- [11:11 \(3 hours ago\)](#)
- [08:46 \(5 hours ago\)](#)
- [16 December 10:03 \(1 day ago\)](#)
- [10 December 10:46 \(7 days ago\)](#)
- [5 December 07:47 \(12 days ago\)](#)
- [10 September 11:08](#)

Click on any of these to view the responses you gave at that time and the feedback you received.

***Thank you very much for your help with this study.***

Please remember that the LIBERATE website **does not replace** the advice and support which you receive from your medical team.

**You should still follow the advice of your doctor or nurse specialist.**

If you are concerned about **ANY** symptoms or side effects which you are experiencing, **please contact your medical team as usual.**

For further support with using the LIBERATE website, or any questions or queries which you might have, please contact the LIBERATE research team during normal office hours (9-5pm, Monday – Friday):

Tel: 0113 20 67580

Email: [um08k2k@leeds.ac.uk](mailto:um08k2k@leeds.ac.uk) (Kathleen Kane, LIBERATE PhD student)

Section of Patient Centred Outcomes Research, level 6 Bexley Wing,

St James's University Hospital, Leeds LS9 7TF