

East Lancashire Prostate Cancer Support Group Newsletter



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Online Intervention to Support People With Prostate Cancer & Ongoing Fatigue

What's Inside

Dear East Lancashire Prostate Cancer Support Group ,

We at King ' s College London, have developed an online intervention to support people with prostate cancer with ongoing fatigue. We are recruiting people with prostate cancer who experience fatigue to take part.

We would like to work with you to advertise this research to East Lancashire Prostate Cancer Support Group.

Please find attached an advert and participant information sheet containing information about this research.

Here is a link to the study website, which contains more detailed information about the study: <https://www.flexproject.co.uk>

Please let me know if it is a possibility to share this advert with the members of East Lancashire Prostate Cancer Support Group.

If you would like to find out more about the project, please contact me on flexproject@kcl.ac.uk and 07950214560. I am happy to answer any questions you have, so please don ' t hesitate to get in touch.

Thank you for your time.

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Patient Information Sheet To Cover Page 1

Article



A novel online program for fatigue; a feasibility study

We would like to invite you to take part in a research study conducted by King's College London. The study will investigate how persistent fatigue can affect how people process information. It will explore whether we can change how the brain processes information using an online computer program.

Before you decide if you would like to participate, we will tell you why the research is being done and what it will involve for you. One of our team will go over this information sheet with you and give you the opportunity to ask any questions.

What is the purpose of the Study?

Research has shown that the experience of ongoing and persistent fatigue can affect how people process information. For some people, it can result in problems with attention and concentration. For others it can cloud how they see everyday activities, making planning and socialising difficult.

This research is interested in whether we can shift how people process information back to how it was before they experienced excessive fatigue. We are interested in whether shifting these processes can help reduce the distress caused by fatigue. We have adapted an existing online program to make it specific to the experience of fatigue. The purpose of this study is to investigate whether this adapted online program is feasible; that is; is the program useful for patients who experience persistent fatigue.

What would taking part involve?

If you agree to take part, you would be asked to complete some computerised training. There are two types of this training and you would be randomly assigned to complete

one of them. One is an active version of the training and one is a neutral version. This is so that we can compare them. Both types of training consist of 12 sessions completed over 3 weeks (4 sessions per week). The sessions will last about 20 minutes and can be completed at home on a computer or tablet. You are able to select the days and time you wish to complete the sessions. In addition, you would complete some assessments online, before and after the 12 training sessions and again at 1-month and 3-months follow-up.

Why have I been invited?

You have been invited because you have experience of persistent fatigue.

Do I have to take part?

No, you do not have to take part. It is up to you if you would like to join the study. If you are interested in taking part, we will ask you to register your interest on the website and sign a consent form. You are free to change your mind and to withdraw at any time. This will not affect your standard of care. You do not have to give a reason for not wanting to take part.

Will my information be kept confidential?

Your personal information will be kept confidential. The questionnaires will be input into a computer. Only the researchers will have access to the computer which will have a password to protect all confidential files. Any personal details or identifiable information will be removed and contact details will be stored separately in a password encrypted file. The data will be kept securely at King's College London. Contact details will be destroyed at the end of the study whilst consent forms will be archived up to seven years after the research has finished.

In the unlikely event of any risk such as self-harm or suicide risk, confidentiality will need to be broken. Your safety is very important. Both you and your clinical team will be made aware of the breach of confidentiality.

Data will also be stored on an online platform. Questionnaires will be completed on Qualtrics whilst the training will be conducted using a website developed and hosted by SPIKA (for privacy statements, please see links: <https://www.qualtrics.com/privacy-statement/>; <https://www.spika.com/privacy-policy/>).

How your personal data will be used in compliance with General Data Protection Regulation (GDPR)

King's College London (KCL) is the lead sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. KCL will keep identifiable information about you for 7 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the Chief In-

investigator Dr Alicia Hughes; alicia.hughes@kcl.ac.uk, or visiting the KCL website: <https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research.aspx>.

If you were recruited from South London and Maudsley NHS Foundation Trust, they will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. South London and Maudsley NHS Foundation Trust will pass these details to King's College London along with the information collected from you. The only people in King's College London who will have access to information that identifies you will be people who need to contact you regarding the research or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

What are the possible disadvantages / benefits of taking part?

The risk of taking part is extremely minimal. You can complete all parts of this study at home. The online program has been used before without any adverse effects. The assessments have also been used previously and should not cause any distress.

The study requires a 3-week time commitment from participants, in order to complete all 12 online sessions. To reduce the burden of this on participants we have made each session as short as possible. There is also a visual calendar built into the website to help you plan to complete these sessions.

This study is investigating whether a program like may be useful for people with fatigue, however in its current form it is not viewed as a therapeutic intervention. Whilst participants may not directly benefit from this study, the research is aimed at further understanding factors which contribute to fatigue. This knowledge can help us identify ways to help reduce the distress and disability fatigue can cause in people's lives.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Alicia Hughes, 0207 188 5422, alicia.hughes@kcl.ac.uk]. If you remain unhappy and wish to complain formally, you can do this through the South London and Maudsley Patients Advice and Liaison Service (PALS) on 0800 731 2864, pals@slam.nhs.uk.

What will happen to the results of the research study?

The results of this study may be published in scientific journals and at medical and psychological academic conferences. You will not be identified in any report or publication. A lay summary will be sent to participants.

Who has reviewed the study?

This study has been checked by Research Ethics Committee, an independent group

of people, to protect your safety, rights, wellbeing and dignity.

Any further queries?

If you have any questions or concerns about the study, you may contact the following organisations

For independent advice on participating in NHS research:

Patient Advice and Liaison Service (PALS) - 0800 731 2864

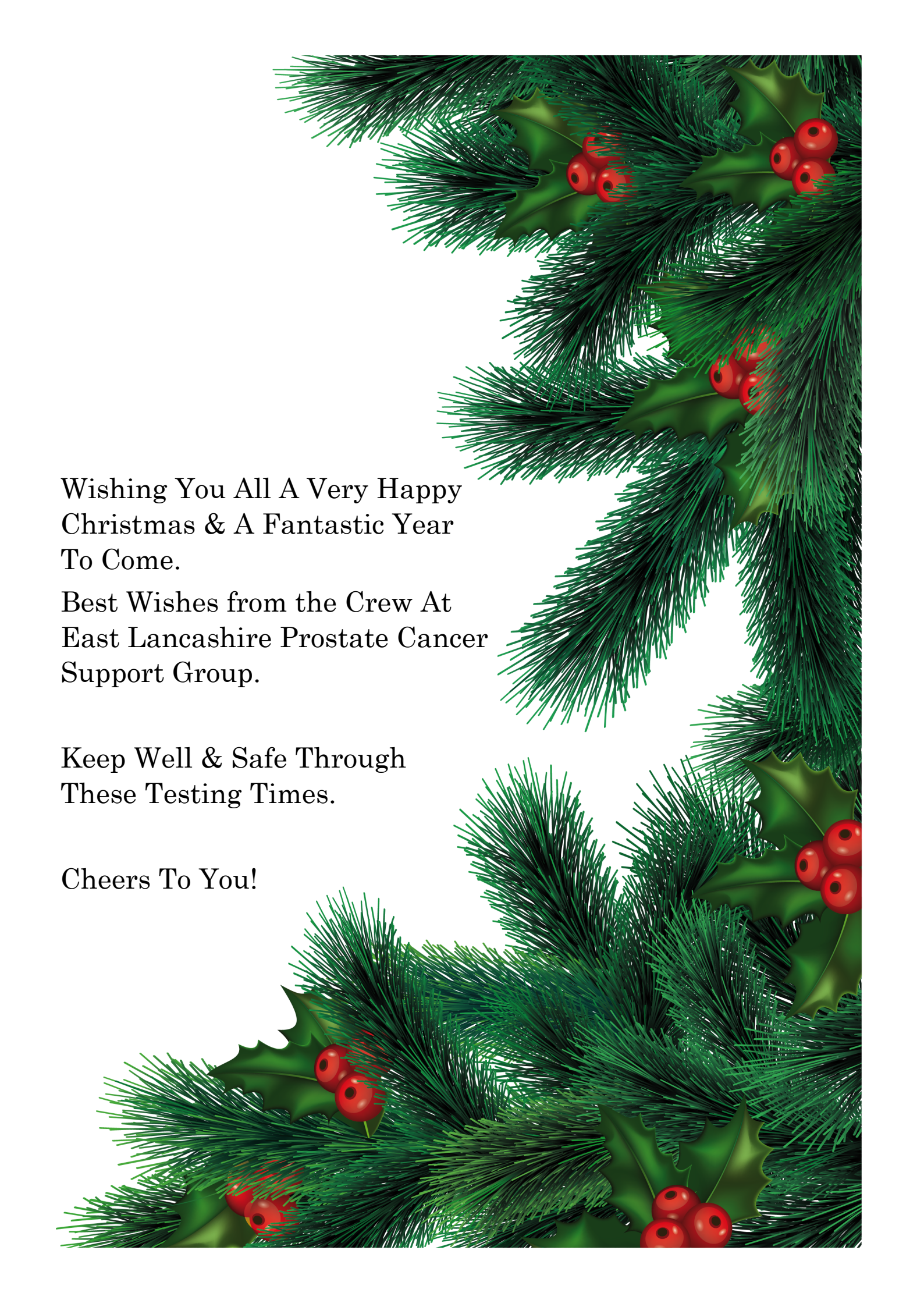
For independent advice about making a complaint:

South London Independent Complaints Advisory Service (ICAS) – 0300 456 2370

For information from the researchers:

Sophie Fawson: TAPPS-study@kcl.ac.uk 0207 188 5422 (Principal Researcher)

Dr Alicia Hughes: Alicia.hughes@kcl.ac.uk 0207 188 5422 (Chief Investigator)



Wishing You All A Very Happy
Christmas & A Fantastic Year
To Come.

Best Wishes from the Crew At
East Lancashire Prostate Cancer
Support Group.

Keep Well & Safe Through
These Testing Times.

Cheers To You!



Contact Information

Tel: 07548 033930
E Mail elpcsginfo@virginmedia.com

From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

Samples Page Laughter

