



Report to the Burdett Trust for Nursing

Men, Work and Cancer: developing a nurse-led action plan on post-cancer diagnosis self-care and self management support for men in paid employment

1. Introduction

1.1 As part of a themed grant programme on Men's Health, the Burdett Trust for Nursing awarded a grant to the European Men's Health Forum (EMHF) to develop a nurse-led action plan to support men who are in paid employment and living with cancer through the development of self-care and self-management programmes. EMHF partnered with Ulster University and Fandangle Films to deliver a literature review, symposium report and resources to support nurses and men.

2. About EMHF

2.1 EMHF is the only European organisation dedicated to the improvement of men's health in all its aspects. Its vision is a future in which all men in Europe have an equal opportunity to attain the highest possible level of health and well-being.

2.2 EMHF has a long history of developing policy and projects on men's health with a particular focus men and cancer and men and primary care. EMHF has been a long-term supporter of HPV Action, a UK consortium of organisations advocating gender-neutral HPV vaccination in order to prevent the growing number of HPV-related cancers in men. Previously EMHF ran Your Prostate, a nurse-led online information and enquiry service for men with prostate problems. Its President, Ian Banks, is honorary senior lecturer in men and cancer at Queens University Medical School, visiting professor in cancer inequalities at Leeds University medical school, board member and chair of the European Cancer Organisation (ECCO) patient advisory committee and vice chair of conference 2017, joint vice president of the European Cancer Concord and a member of the European Society of Medical Oncologists' (ESMO) patient advocacy committee.

3. Rationale for the project

3.1 Men are much more likely than women to develop and die from cancer. Survival rates are improving, however, and many more men are living for longer with cancer. This trend coincides with a rising retirement age in the UK and across Europe, meaning that increasing numbers of men with cancer are and will be in work. It is therefore essential to develop interventions that support men living with cancer who are in work with self-care and self-management. These interventions can promote healthy living and enable men to self-manage cancer disease and treatment symptoms and remain within the workforce.



- 3.2 For some men returning to work is fundamental in the recovery process after a diagnosis of cancer. The issue of how best to enable men with cancer to remain in paid employment has not been addressed before.
- 3.3 One of the many decisions that individuals may have to make after finishing treatment for cancer is if and/or when they will return to work (RTW). Work is good for health. Not only because it provides a source of income, it also preserves a sense of identity and purpose (Spence 2017)¹ especially, if someone is going through a difficult period. Work provides social interaction and, especially in the case of someone who has struggled through cancer, a sense of normality. As Wilson (2014)² alludes to, work contributes to financial independence, provides a sense of purpose, gives an individual identity and self-esteem, creates structure and order in their lives, is an important source of friendship and social interaction, and is a lifeline back to normality, wellbeing and recovery.
- 3.4 Employers also benefit from supporting employees post cancer diagnosis. Research shows that people who have had treatment for cancer are as productive as people who have not had cancer, they take less time off work than other employees, and in general, perform well in the workplace. (Shulz, P. et al 2002)³
- 3.5 When men have been diagnosed with cancer, workplaces have a legal and ethical responsibility to make appropriate changes to working practices. In the UK men and women returning to work following cancer are protected from discrimination in the workplace by the Equality Act 2010 (England, Scotland and Wales) and the Disability Discrimination Act 1995 (Northern Ireland).
- 3.6 Under the Acts, a diagnosis of cancer is considered as a disability and because of this employees with cancer can discuss with their employer legitimate changes to their work arrangements and/or place of work. However, to enable such changes to be implemented the employee must inform their employer of his/her diagnosis and the changes need to be practical for the employer, in terms of cost. How the change will impact on other workers also needs to be taken into consideration
- 3.7 Men living with cancer should also benefit from other support provided in the workplace, such as counselling and advice and information about self-care and self-management. Research suggests that many men prefer male-targeted and male-specific self-care interventions.⁴ The workplace is also known to be an effective setting for engaging men.

¹ Spence L (2017) Living well: Returning to work after cancer. BUPA. Available at <https://www.bupa.co.uk/newsroom/ourviews/returning-work-after-cancer>

² Wilson B. (2014) Work after cancer: what are the options and how can employers help? The Guardian. Available at: <https://www.theguardian.com/society/2014/apr/09/work-after-cancer-options-employers>

³ Shulz, P. et al (2002), Cancer Survivors – Work-related Issues, American Association of Occupational Health Nurses Journal

⁴ Robertson, S and White, A and Gough, B and Robinson, R and Seims, A and Raine, G and Hanna, E (2015) *Promoting Mental Health and Wellbeing with Men and Boys: What Works?* Project Report. Centre for Men's Health, Leeds Beckett University, Leeds. DOI: 978-1-907240-41-6 (ISBN)



- 3.8 Returning to work after treatment for cancer can be difficult both mentally and physically. Duijts et al. (2016)⁵ and others have identified that work-related, disease and treatment related and person-related factors are all determinants that can influence whether someone will return to work post treatment diagnosis. Macmillan (2013)⁶ reported that not enough people with cancer are receiving general work-related support or more specialist help despite over a quarter stating they would have found it helpful to access return-to-work support services.
- 3.9 Every case is different but there are some common issues employers and those with cancer need to be aware of, such as dealing with the side effects of treatment, which can be both physical and psychological and which can begin long after treatment has finished. Previous studies have identified that patients with cancer have concerns about their ability to return to work, losing their job,⁷ disclosing their diagnosis to their employer and their physical appearance (Tiedtke et al. 2010).⁷ Some may not have the same energy level as before (Aaronson 2014)⁸, and/or may experience side effects such as chemo brain, which can make it difficult to concentrate and think clearly (Fitch and Nicholl 2014)⁹.
- 3.10 In response to the increasing prevalence of cancer among the working population employers and health professionals have a pivotal role to play therefore, there needs to be rigorously tested intervention strategies to support individuals remain in employment and return to work post cancer treatment. With the increase in the retirement age many men are part of a growing community of cancer survivors who are employed or self-employed, are on sick leave, and have a desire to return to work. Given that men experience and express their psychological needs and motivations differently from women then interventions to meet their needs require to be male specific (BMA NI 2011; Hartley-Folz 2014)¹⁰.

4. The role of nurses

- 4.1 Nurses play a key role in occupational health and are considered to be leaders in public health in the workplace setting. Many work in organisations which employ significant numbers of men; indeed, some will be in industries where most of the staff are male (e.g. construction, transport, engineering, heavy industry). However, most have not received training in men's health or have

⁵ Duijts SFA, van Egmond MP, Gits M, van der Beek AJ and Bleiker EM. (2016) Cancer survivors' perspectives and experiences regarding behavioral determinants of return to work and continuation of work. *Disability and Rehabilitation*, DOI: 10.1080/09638288.2016.1219924

⁶ Macmillan Cancer Support (2013) Making the shift: Providing specialist work support to people with cancer. Available at: <http://www.macmillan.org.uk/documents/getinvolved/campaigns/workingthroughcancer/making-the-shift-specialist-work-support-for-people-with-cancer.pdf>

⁷ Tiedtke C, de Rijk A, Dierckx de Casterlé B, Christiaens M. and Donceel P. (2010) Experiences and concerns about 'returning to work' for women breast cancer survivors: a literature review. *Psycho-Oncology*, 19(7):677-683.

⁸ Aaronson NK, Mattioli V, Minton O, Weis J, Johansen C, Dalton SO, Verdonck-de Leeuw IM, Stein KD, Alfano CM, Mehnert A, de Boer A. and van de Poll-Franse LV. (2014) Beyond treatment: Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer*, 12(1): S54-64.

⁹ Fitch M. and Nicoll I. (2014) Returning to work following cancer treatment: perspectives of survivors and employers, *Psycho-oncology*, 23(1): S54-55.

¹⁰ British Medical Association (BMA), Northern Ireland (2011) Improving men's health in Northern Ireland. Available at: <http://www.southerntrust.hscni.net/images/bmamenspolicy.pdf>



adapted their services to take account of gender differences and men specifically. The aim of the project was to empower nurses by providing them with resources for effective work with men living with cancer in the workplace.

There are approx. 750,000 people of working age in the UK living with cancer.

- Cancer is more common in men than women. In the UK, Men have a 14% higher risk of developing cancer and a 37% higher risk of dying from cancer than women.
- Cancer Research UK research suggests that by 2027 half of all men will get cancer in their lifetime.
- More than half of new cases of cancer in males are prostate, lung or bowel cancer.
- People now live nearly ten times longer after their cancer diagnosis compared to 40 years ago
- The UK cancer survival rate is lower for men than for women and below the European average.

5. Methodology

5.1 The project was overseen by a project steering group comprising of nurses, health professionals and men living with cancer while in work.

5.2 Membership

Prof Ian Banks, President of Europeans Men's Health Forum

Dr Steve Boorman, Director of Employee Health for Empactis

Mr Raymond Bothwell, Patient Advocate

Mr Brian Conway, Patient Advocate

Mr Pat Hamill, Patient Advocate

Dr Briega M Lagan, Lecturer in Nursing & Public Health, Ulster University

Prof Eilis McCaughan, Professor in Cancer Care, Ulster University

6. Literature Review

6.1 To assess what was already known about this issue and what interventions have been previously implemented in the UK and elsewhere, a literature review and mapping exercise was conducted by Dr Briega M Lagan, Lecturer in Nursing & Public Health, Ulster University.

6.2 The purpose of the scoping study was to collate and review the evidence pertaining to interventions that have been designed to support those in paid employment after a diagnosis of cancer. The outcome of interest in the review were interventions that specifically supported men diagnosed with cancer to remain in employment and return to work.

Research questions

The review was guided by the following questions:

1. *What is known from existing literature about interventions to support those in employment and/or return to work following a diagnosis of cancer?*

2. *What good practice strategies could be employed to develop a nurse-led action plan to support men who are in paid employment and living with cancer?*



3. What are current research priorities?

6.3 Conclusions

- Returning to work after cancer can be a complex phenomenon that can be influenced by the persons own attitudes and beliefs and various stakeholders.
- There was to date no 'male specific' interventions identified from the literature to support men that have survived cancer to remain in employment therefore it was not possible to compare with the available data the difference between men-only and mixed-sex interventions.
- Men may need different information and support depending on where they are on their cancer journey. There is a need to consider what systems could be developed to deliver effective vocational rehabilitation interventions specifically for men who need additional help to return to work.
- Many of the interventions were described in sufficient detail that they could be applied to the male population. However, what men like and do not like e.g. the use of language and humour need to be considered when adapting the design and content of any intervention that was previously developed for a different population. Such adaptation would require rigorous fidelity checks.

6.3 Recommendations

The recommendations were based on the overall aim and findings from the review. In order to ensure that men with cancer are supported to remain in or return to work the following recommendations are made:

- Men need a specially designed package. Many of the interventions identified from the review were described in sufficient detail that they could be applied to the male population. However, what men like and do not like e.g. the use of language and humour need to be considered when adapting any design and content of an intervention that was previously developed for a different population. Such adaptation would require rigorous fidelity checks.
- In addition to being 'gender' specific any intervention also needs to take into consideration other socio-demographic attributes such as age and the type of cancer and treatment the person has had as such factors can affect a cancer survivors employment and work ability. It is important that any intervention has the capacity to be tailored to meet any changing needs during the individual's cancer journey.
- When designing the intervention a comprehensive and systematic approach should be used. All relevant stakeholders should be consulted so they can give a practical insight on what would work and what would not. This includes including users (men) who have had cancer and have returned to work. There needs to be shared decision-making and the recognition that patients and clinicians bring different, but equally important knowledge and expertise to the return to work process.
- The developed intervention needs to consider all dimensions of health literacy so all users can be empowered make informed and appropriate work related decisions and are able to



avail of the support offered and needs to incorporate:

- Sections specific for the employed/unemployed and self employed
- Creating a return to work plan and what needs to be included in the plan e.g. negotiating a phased return to work, change in role within workplace, changes to physical working environment, flexible working hours
- How to keeping the channel of communicating open with their employers
- Up to date quality information and support that delivers positive and well informed messages about work, when can return to work and what to expect when returns to work
- Disability law
- Sign post to different support available e.g. financial, legal, psychological, career advice
- The intervention should include multidisciplinary support, including medical, psychological, occupational and rehabilitation support.
- Creative approaches to promote and encourage men to engage in interventions to support them should be considered e.g. use of social media or Telenurse.
- The intervention should be implemented in the early stage of treatment.

6.5 Health Professionals:

- Health professionals especially oncology nurses and doctors need knowledge to provide support to men and time to provide that support. If this is not possible then there should be a lead professional should be appointed specifically for that role
- Health professionals need to know what support mechanism are available within their locality and how to sign post men to such organisations
- There needs to be effective channels of communication and open and transparent conversations between health professionals; and between health professionals and the patient; and with the patients consent between the health professional and the patient's employer/occupational physician to facilitate the transition from the clinical environment towards the working environment for cancer survivors

6.6 Employers:

- Employers and/or line managers need to be involved in the return to work process
- Employers and line managers should have information and training about what to expect and manage someone returning to work after a cancer diagnosis.

6.7 Areas for further research

In the process of conducting this review, several gaps in the existing research knowledge about RTW interventions were identified:



- There is a need male specific interventions that can be evaluated using robust methods to make comparisons between the effectiveness of men-only and mixed-sex interventions.
- Although some of the existing studies on return to work interventions for patients with cancer were potentially successful in improving return to work rates but there was limited evidence that any had a significant impact on quality of life. This area needs explored further.

6.8 The findings of the literature review were considered by the Project Steering Group and presented to the expert symposium.

6.9 See Appendix 1 for the full literature review.

7. Men, Work and Cancer Symposium

7.1 An expert symposium was held at the Royal College of Nursing on 12th June 2017. The aim of the meeting was to draw on the expertise and experience in the room to support the development of a health information resource for men returning to work or staying in work after a cancer diagnosis. The resource would be designed to appeal to men and also for nurses, occupational health and employers to use with male employees to help facilitate their choices around work.

7.2 The key speaker was Professor Dame Carol Black, Principal of Newnham College, Cambridge and special advisor to the Department of Health and Public Health England. Dame Carol presented on cancer as a chronic disease and how good work aids recovery and can lead to better health outcomes.

7.3 Participants also heard from Dr Ian Banks, Dr Brieger Lange, Fandangle Films and Jim Pollard who all contributed to providing context and background information to inform the workshop discussion on the development of resources.

7.4 The workshop discussions were introduced by Dr Steve Boorman, Director of Employee Health for Empactis and Honorary Professorial Fellow of the Royal Society of Public Health. He asked the participants to consider the following areas for developing health information resources for men returning to work after a cancer diagnosis:

- What should we include in the manual, where are the gaps, what is the need?
- How to implement the manual, distribution and dissemination.
- Suggested ways to evaluate the manual
- Potential challenges and solutions The participants divided into three tables to discuss the questions. Patient advocates were represented on each table

7.4 Proceedings of the event were captured in a report (See appendix 2) and the findings were incorporated into the development of the resources. Both the promotional video and '*Working with Cancer*' guide was informed by the process.



8. Developing resources: Working with Cancer: a guide for men during and after diagnosis

- 8.1 The findings of the literature review, the expert symposium and the project steering group and an understanding of how to communicate to men were taken by the writer, Jim Pollard to develop the structure and content for a guide. Jim Pollard is an award winning writer and journalist who specialises in men's health and has experience of having a cancer diagnosis.
- 8.2 Drafts of the guide structure and content were considered by participants of the symposium and the steering group with opportunities to feedback at each stage.
- 8.3 Jim also interviewed men with cancer diagnoses from the steering group and other contacts to ensure that the resource and content worked for them.
- 8.4 A final draft of the guide was agreed by the Project Steering Group for publication.
- 8.5 Organisations engaged in the symposium and consultation and other relevant organisations across Europe were invited to support, endorse and disseminate the guide. Over 25 key organisations provided their logos and supported through dissemination (see below)

9 Developing resources: Social media video: Working with Cancer

- 9.1 Fandangle films was commissioned to develop a short promotional film for the guide targeted at a pan-European audience, with the brief to create a story devoid of speech so that anybody could understand its message.
- 9.2 Fandangle films worked with the Steering Group, the writer and men with cancer to ensure content was reflected in the film and the most up to date material was used. The aim was to tell a story of a man returning to work after a cancer diagnosis, the difficulties he faced and how using the guide helped ease that return and to help have conversations with his nurse and his employer.
- 9.3 Conveying the message without language was not easy through visuals alone. To convey some of the more nuanced ideas several visual devices were used, one of which was a mirror. When the character first wakes up, he appears to be healthy and in a cheery mood, ready to take on the day. It isn't until he sees his reflection that he realises the reality of his situation: He's suffering from cancer and has to live his life within the parameters that his illness puts upon him. The incongruity between how we see him at first and his true appearance highlights the fact that although cancer has a reputation for being incredibly restrictive, men still want to continue their lives as normal. He may look sickly and incapable, but he desires to work and to feel useful, which is one of the core messages of the video. At the end of the film, we had the



character look briefly into the mirror as he heads for work, pleased that he's dressed and ready. This not only served as a nod to the beginning, but shows how, although the character is not free from cancer, he is now free to go to work and live his life the way he wants.

9.4 The video is posted on the EMHF YouTube channel at
https://www.youtube.com/watch?time_continue=2&v=D2c7CRMGWMMU
<http://emhf.org/new-guide-working-with-cancer/>

10 Publication and dissemination

10.1 The Working with Cancer guide and video were published on 23 November 2017J. It was made available online at the EMHF website www.emhf.org along with existing information about the project, including the symposium report.

10.2 A press release was sent to relevant health and corporate organisations, media and specialist health journalists. The press release included quotes from Dr Ian Banks, Prof Dame Carol Black and The Burdett Trust.

10.3 The guide and vide were circulated electronically to a wide network of supporters, organisations and individuals for dissemination. Many organisations such as BT, the Royal College of Nursing and ECCO were able to further disseminate across their own networks and organisations.

10.4 Social media channels were utilised. The EMHF Twitter account promoted the resources and partners organisations were provide with sample Twitter messaging and pictures to use. Links to Tweets from partner organisations and other followers:
https://twitter.com/HelenDon_RCN/status/935795247770107904
<https://twitter.com/behealthyatwork/status/940930781932900352>
https://twitter.com/europa_uomo/status/933677192726401024

10.5 Many partner organization ran their own news stories on websites:
Men's Health Forum Ireland:

<http://www.mhfi.org/news/798-working-with-cancer-booklet-for-men.html>

Malta Association of Public Health Medicine:

<https://maphm.org/2017/12/08/working-with-cancer-a-guide-for-men/>

Men's Health Forum UK:

<https://www.menshealthforum.org.uk/news/men-work-cancer>

Patient Information Forum UK:

<https://www.pifonline.org.uk/new-guide-working-cancer-haynes-manual/>

Europa Uomo:

<https://www.facebook.com/EuropaUomo/posts/609662199157607>

Royal College of Nursing:

<https://www.rcn.org.uk/news-and-events/news/new-manual-to-support-men-with-cancer-at-work>



- 10.6 The project manager, Tracy Herd, produced a blog for the European Patient Forum on the project and the resource. This appeared in their January 2018 Newsletter, disseminated across Europe <http://www.eu-patient.org/blog/?p=788>
- 10.7 Dr Ian Banks has presented the project to a number of European conferences and events including to Members of the European Parliament on 29th and 30th January 2018.

11 Next Steps

- 11.1 Further funding has been secured to roll out a 'Working with Cancer' project across Europe. The initial activity will include a further literature review and expert symposium, bringing together experts from across Europe to discuss support for men returning to work after a cancer diagnosis and how a European wide approach can be developed.
- 11.2 Funding is also being sought to then take forward the findings of both the literature review and the symposium and produce resources to use across Europe.
- 11.3 The Men's Health Society of Denmark, a member of the European Men's Health Forum, has expressed interest in hosting an expert symposium and producing the guide in Danish.

**European Men's Health Forum
February 2018**



References

Aaronson NK, Mattioli V, Minton O, Weis J, Johansen C, Dalton SO, Verdonck-de Leeuw IM, Stein KD, Alfano CM, Mehnert A, de Boer A. and van de Poll-Franse LV. (2014) Beyond treatment: Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer*, 12(1): S54-64.

British Medical Association (BMA), Northern Ireland (2011) Improving men's health in Northern Ireland. Available at: <http://www.southerntrust.hscni.net/images/bmamenspolicy.pdf>

Duijts SFA, van Egmond MP, Gits M, van der Beek AJ and Bleiker EM. (2016) Cancer survivors' perspectives and experiences regarding behavioral determinants of return to work and continuation of work. *Disability and Rehabilitation*, DOI: 10.1080/09638288.2016.1219924

Fitch M. and Nicoll I. (2014) Returning to work following cancer treatment: perspectives of survivors and employers, *Psycho-oncology*, 23(1): S54-55.

Macmillan Cancer Support (2013) Making the shift: Providing specialist work support to people with cancer. Available at:

<http://www.macmillan.org.uk/documents/getinvolved/campaigns/workingthroughcancer/making-the-shift-specialist-work-support-for-people-with-cancer.pdf>

Mehnert A, de Boer A. and van de Poll-Franse LV. (2014) Beyond treatment: Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer*, 12(1): S54-64.

Robertson, S and White, A and Gough, B and Robinson, R and Seims, A and Raine, G and Hanna, E (2015) *Promoting Mental Health and Wellbeing with Men and Boys: What Works?* Project Report. Centre for Men's Health, Leeds Beckett University, Leeds. DOI: 978-1-907240-41-6 (ISBN)

Shulz, P. et al (2002), Cancer Survivors – Work-related Issues, *American Association of Occupational Health Nurses Journal*

Spence L (2017) Living well: Returning to work after cancer. BUPA. Available at <https://www.bupa.co.uk/newsroom/ourviews/returning-work-after-cancer>

Tiedtke C, de Rijk A, Dierckx de Casterlé B, Christiaens M. and Donceel P. (2010) Experiences and concerns about 'returning to work' for women breast cancer survivors: a literature review. *Psycho-Oncology*, 19(7):677-683.

Wilson B. (2014) Work after cancer: what are the options and how can employers help? *The Guardian*. Available at: <https://www.theguardian.com/society/2014/apr/09/work-after-cancer-options-employers>



Appendices

Appendix 1: Interventions to Support Cancer Survivors Remain in Employment: A Scoping Review of the Literature. Dr Briega M Lagan, Ulster University

Appendix 2: MEN, WORK & CANCER - Developing a post-cancer support manual for men
Report of an EMHF symposium held 12 June 2017 at the Royal College of Nursing

Appendix 3: Working with Cancer: A guide for men during and after diagnosis