



# 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



## EXECUTIVE SUMMARY

In 2016 the European Men's Health Forum (EMHF) was awarded a grant by The Burdett Trust for Nursing as part of their themed grant programme on men's health 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.

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.

When men have been diagnosed with cancer, workplaces have a legal and ethical responsibility to make appropriate changes to working practices. 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. The workplace is known to be an effective setting

for engaging men.

A part of this project, key stakeholders were brought together for a symposium on men, work and cancer at the Royal College of Nursing on 15th 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.

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.

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

# BACKGROUND

In 2016 the European Men's Health Forum (EMHF) was awarded a grant by The Burdett Trust for Nursing as part of their themed grant programme on men's health 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.

## Rationale for the project

Men are much more likely than women to develop and die from cancer. Survival rates are improving, and many more men are living 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.

When men have been diagnosed with cancer, workplaces have a legal and ethical responsibility to make appropriate changes to working practices. 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. The workplace is also known to be an effective setting for engaging men. The issue of how best to enable men with cancer to remain in paid employment has not been addressed before.

## The role of nurses

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/ companies which employ significant numbers of men (e.g. construction, transport, engineering, heavy industry). However, most nurses and occupational health staff have not received training in men's health or have adapted their services to take account of gender differences and men specifically. The project will empower nurses by providing them with a self-help guide to support men living with cancer in the workplace, a resource that is not currently available elsewhere.

## Project Outcomes

The principal outcomes to date are:

- A literature review that reviewed evidence pertaining to interventions that have been designed to support cancer survivors remain and/or return to work.
- A symposium and report that brought together key experts and stakeholders to input to the development of resources.

Further project outcomes will include:

- The publication and dissemination of a self-help guide specifically for men of working age with cancer which nurses and others can use to support their work.
- Adoption of the action plan by a wide range of relevant organisations.

## Key Issues

The incidence of cancer is increasing as populations grow and age. At the same time earlier detection and improved treatment options are contributing to better survival rates and the numbers of people living with cancer is rising.

This, along with the rising retirement age, means more cancer survivors of working age and looking to return to work after diagnosis and treatment.

For some men returning to work is fundamental in the recovery process after a diagnosis of cancer.

## The statistics

- 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.

# PROCEEDINGS

## Welcome from the Chair

Dr Ian Banks, President of the European Men's Health Forum welcomed participants to the symposium and to

the Royal College of Nursing.

He started by remarking that it was a delight to be at the Royal College for the event and reminded the audience that the Men's Health Forum was founded at the Royal College of Nursing by Christine Hancock over 20 years ago, starting as the Men's Health Committee and eventually becoming an independent charity in 2001.

He proceeded to give an overview of the Men, Cancer and Work project, thanking the Burdett Trust for Nursing for funding the work and explained the purpose of the day's proceedings.

Dr. Banks highlighted the importance of work and the workplace for men at the same time recognising the importance for women too. He stated that the workplace is an ideal setting for engaging men with their health, to get them talking about their health and improving their health. Good work supports good health. He raised the issue of men not using primary care and other health services as readily as women which often leads to late presentation and poorer health outcomes for men. A good example of the impact of this behavior is the similar rates of incidence of malignant melanoma in men and women but the difference in mortality rates, with them being considerably higher in men.

He reminded the audience that breast cancer kills more men than testicular cancer each year, yet many men do not even know that they can be diagnosed with breast cancer let alone recognise signs and symptoms and this needed to change with more awareness and quality health information targeted at men to get the message across.

He concluded with the good news that although the incidences of cancer are increasing, survival rates are increasing and treatment is improving. Coupled with the changes to state pension ages more men will consider staying in or returning to work after a cancer diagnosis. When asked, men are clear that returning to work is something that is important to them.

## KEYNOTE ADDRESS

### Carol Black: Changing attitudes to work, illness and disability. Are we making progress?

**Professor Dame Carol Black, Principal of Newnham College, Cambridge and special advisor to the Department of Health and Public Health England.**

Dame Carol thanked Ian for the opportunity to speak at the symposium and introduced her presentation. She stated that she would be looking at cancer as a chronic disease and how good work can aid recovery and can

lead to better health outcomes. She made the following points:

#### Good Work supports good health

- For those with chronic disease or disability work can reduce the risk of chronic disability and long-term incapacity, reduce poverty and social exclusion and improve quality of life and well-being.
- You do not have to be 100% fit to work.
- Work needs to be good work and enabling people to be in work is a health issue.
- Primary care services need to acknowledge the role work and employment has in improving health outcomes.
- Work in itself has value as it provides, income, material well-being and participation in society.
- Employment and socio-economic status are the main drivers in the social gradients in health.
- The gap in the employment rate between UK people with a disability (47%) and the rest of the working-age population (80%) is wider than most other European countries.

#### Worklessness is a risk to good health

- Long-term worklessness is greater risk to health than the 'killer diseases'.
- Worklessness leads to social exclusion and poverty and those without work have two to three times the risk of mental illness than those in work.
- Transgenerational worklessness is of particular concern – 'we in this house do not work, if you work you cannot live here'.

#### What prevents people working?

- There is a continuum of factors that prevents people from working from; common mental illnesses, common musculoskeletal problems, and chronic medical conditions through to major functional incapacity.
- Coupled with the social determinants of health and potentially poor workplaces, poor work and poor managers keeps people out of work.
- A cancer diagnosis may come with other chronic conditions, the combination of which mean that people will be less likely to be in work or return to work.

#### Cancer is a Long Term Condition

- Long term conditions (LTCs) (of which cancer can be categorised as survival rates increase) account for over 70% of health and social care spending and approx. 15 million UK people have at least one LTC.

- Analysis of the Health Survey of England by the Fit for Work coalition shows that employment rates decrease with the number of LTCs.
- The number of LTCs increases for people living in areas of deprivation.

### **Cancer and Work**

- 775,000 UK people of working age have had a cancer diagnosis.
- 82% of people with cancer want to work BUT
- Unemployment is 1.4 times more likely for long-term cancer survivors.
- Often their cancer prevents them working in their preferred occupation.
- The average fall in household income for a family with working-age cancer is 50% and 17% lose their home.

### **Example of work disability and benefit claims after early Rheumatoid Arthritis**

- Study showed loss of employment and an increase benefit claims after RA.
- Work disability was predicted by pain and low vitality.
- This was preventable through better pain management by medics.

### **Supporting participation in work needs:**

- Employees who are health seeking and have knowledge about their condition.
- Work- knowledgeable health professionals need to ask the right questions – Would you like to work? How can I help?.
- Employers who create good work and good workplaces.
- Supportive Government action.
- The Access to Work programme is the best-kept secret!

### **Health Professional knowledge and the need:**

- To understand that work is a determinant of health.
- To see a return to functional capacity (work) as an indicator of clinical success.
- To understand that you do not have to be 100% fit to work.
- To ensure early intervention.
- To consider psychosocial problems and the work environment.
- To change medical training curricula and practice to include work as a health outcome.

### **Employer understanding**

- Employers need to understand the link between LTCs and symptoms such as chronic pain, anxiety, stress, depression and fatigue.
- Employers need to be aware of legislation and rights at work of those with LTCs including cancer.
- Macmillan has excellent employer support materials.

### **Potential of the workplace to improve health and wellbeing**

- 31 million employees in the UK plus their families.
- A culture of good health at work can reinforce positive health behaviours.
- Workplaces can utilise powerful communication channels.
- Potential for positive social interaction and support.
- A good workplace will have buy-in and engagement from senior board members and leaders for positive health at work.
- It will consider both mental and physical health improvements.
- It will enable engagement and empower employees to care for their own health.
- It will measure and evaluation impact and outcomes.
- It will understand the importance of mental health awareness and the impact poor work practices and management can have on employee wellbeing.
- Addressing employee health and wellbeing can sometimes mean addressing the social determinants of health, training and skills as well as addressing poor physical health.

### **The impact of addiction**

- Long-term conditions include addiction.
- Addiction is a chronic condition not a life choice.

### **Government Plans**

The Work and Health Green Paper 2016 includes the following proposals:

- That people with disabilities and/or LTCs have full access to labour market opportunities and support.
- That people have personalised access to the right employment and health services, at the right time.
- To integrate more effectively health and social care and welfare systems.
- To invest in innovation.
- To help employers take action to manage an ageing workforce.
- To change cultures and mind-sets across all of society.

## What is good work?

- Stable and safe - not precarious
- Individual control over what you do at work and part of the decision making
- Work demands – quality and quantity
- Fair employment – earnings and security
- Flexible arrangements – where possible
- Opportunities – training, promotion, growth within a role
- Promote Health and Wellbeing – mental and physical
- Prevents social isolation, discrimination and violence
- Shares information – participation in decision making, collective bargaining, justice in conflicts
- Reintegrates sick or disabled wherever possible

Dame Carol concluded her presentation reiterating how important good work is for good health and that the opportunity of returning to work after illness or diagnosis was a key factor in recovery. 'People want to think there is a future for them at work after illness'

## Q&A with Dame Carol Black

Ian Banks made a comment on the importance of recognising that cancer patients are often living with other long-term conditions and that primary care has a significant role in cancer management.

In reply to a question from Professor Eilis McCaughan on employers and difference for big organisations and small and medium sized enterprises (SMEs) with supporting return to work, Dame Carol acknowledged that it was often difficult for smaller employers to support employees to return to work after illness. There was often lack of occupational health support and limited options for flexible return to work options or alternative job roles. She suggested that more focus was needed on involving SMEs with the wellbeing at work agenda and educating them on what was involved in supporting employees to return to work after a diagnosis of a long-term condition.

Isabella Lebrocquy stated that she was a cancer survivor and had lost her job as a result of her diagnosis and experience. She set up a social enterprise, oPuce, in the Netherlands to support people in the same position as she found herself. She suggested that governments needed to play a more central role, helping employers, especially SMEs, with financial and occupational health support in order to support employees better.

Dr Ali Hashtroudi, from Guys and St Thomas Hospital, suggested that work should be recognised and used more as a health outcome.

Dame Carol Black called for a campaign to support this suggestion calling for recognition from NICE. She expressed her disappointment that the recent

government Industrial Strategy Green Paper had no mention on the health and wellbeing of the workforce.

Professor Anne Harriss, South Bank University commented on the need for the curricula for health professionals to change to include a focus on the role of work in recovery. Dr. Ian Peate, Editor of British Journal of Nursing, supported the call suggesting a need for creativity and innovation to be added to the 'activity of living' nursing model.

Dame Carol agreed with both speakers on the need to bring recovery and the role of work into professional teaching.

## REVIEW OF THE LITERATURE

Lecturer in nursing and public health Dr Briega Lagan presented the findings of a literature review and expert focus groups into interventions to support cancer survivors return to work undertaken by Ulster University as part of the project. She made the following points:

The purpose of the review was to collate and review evidence pertaining to interventions that have been designed to support cancer survivors remain and/or return to work.

To identify interventions that specifically supported men diagnosed with cancer to remain in employment and return to work.

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 intervention to support men who are in paid employment and living with cancer?
- 3. What are current research priorities?

Following searches of bibliographic databases for primary literature and the Goggle search engine, and multidisciplinary open access repositories for secondary literature 31 Interventions were identified

The key finding was that no male specific interventions were identified. Emergent themes identified:

- The need for tailored interventions
- Multi-disciplinary interventions
- Effective, sensitive communication
- The importance of completing a Return to Work Plan
- The benefits of 'sign-posting'

Dr Lagan raised some issues to consider for the development of the manual:

- Not everyone may want to return to work.
- Sections specific for the employed/unemployed and self employed.

- Acknowledge socio-demographic attributes such as age and the type of cancer and treatment the person has had.
- Acknowledge all cultures and dimensions of health literacy.
- Has the capacity to meet any changing needs during an individual's cancer journey.
- Consulting all relevant stakeholders so they can give a practical insight on what would work and what would not.

Dr Lagan suggested that the proposed Nurse-led self-help manual needed to include:

- How to navigate through the journey from cancer diagnosis to making decisions about returning to work.
- Up to date 'quality' information and support that delivers positive and well-informed messages about the return to work process.
- How to keep the channel of communicating open with employers.
- Sign posts to the different support available.
- How to create a return to work plan.

She raised a number of challenges and issues to consider for men returning to work after cancer.

## DEVELOPING THE MANUAL

Ian Banks introduced the concept of the manual stating the need to recognise the difference between how men and women relate to their health and health messages.

The manual will be designed to be used by men with a cancer diagnosis but also by health professionals and employers in order to support the men they are working with. He stated that the guide would be written to appeal to men, so that it would be something they would want to pick up or click on and act upon. The manual was an enablement tool not a definitive guide to all things about cancer and the workplace.

Ian introduced Jim Pollard, Editor of the Men's Health Forum Website and an award-winning journalist specialising in men's health information and promotion. Jim gave an overview of the approach he had taken to create a draft outline of the manual for discussion. Jim spoke about his own experience of a cancer diagnosis and returning to work as a self employed freelance writer.

He made the following points:

- It was important for the look and feel of the manual to appeal to men in order for them to engage and to be able to take them where we need them to go.
- He had included three aspects that the evidence and his experience suggested needed to be included –

the physical aspects of cancer, the physiological aspects of cancer and decisions about returning to work or staying in work after a cancer diagnosis.

- He thought the manual needed to support men through the journey from diagnosis through to the possibility of returning to work.
- It was important to get the language and tone of the manual right for men.
- A key message needed to be that you are no lesser man if you decide not to return to work.

## USING FILM

Peter Banks and Sisley Henning of Fandangle Films introduced a storyboard for a short animation film designed to promote the use of the manual. The eventual aim would be to use the film across Europe through social media, networks and partnerships. Peter explained that the idea was to direct men and those working with men towards the manual with minimal use of language so that it would translate well across European countries.

The film was discussed during the roundtable sessions.

## ROUNDTABLE DISCUSSIONS

Dr Steve Boorman, Director of Employee Health for Empactis and Honorary Professorial Fellow of the Royal Society of Public Health introduced the discussion on developing health information resources for men returning to work after a cancer diagnosis reminding participants of the need to think about the following:

- 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. Some of the issues and suggestions highlighted were:

### What should we include in the manual, where are the gaps, what is the need?

- Emphasising the value of work and positive messages around recovery and return to work (RTW) rates
- A plan of action and questions to ask your employer
- Peer support – stories of men real life experience about how they went back to work, what support they needed, what happened?

- A 'who can help?' section
- A positive tone about the chances of RTW
- Not returning to work – Who can help, what are the alternatives?
- Managing physical symptoms at work
- Impact of treatment on the length of time off work
- Knowing your rights
- Working through treatment
- How to communicate with your employer about your diagnosis and continue regular communication about how you are feeling and the consequences of treatment
- Top ten tips for staying in/returning to work

### How to implement the manual, distribution and dissemination.

- Social media/Twitter/Linkedin
- Peer networks
- Professional journals
- WHO EU – (PHE Chief nurse directorate is a collaborating centre)
- Key stakeholder organisations RCN, QNI, Burdett Trust, PHE, Cancer Charities, Society for Occupational medicine etc.
- Health Professionals
- Quick bit of research of patient pathway and see who they see at the critical times for intervention
- Via training platforms for occupational health nurses
- Trade Unions
- Carers/wives/partners/family
- Industry

### When should men be made aware of the manual?

- As early as possible in diagnosis – treatment phase - but would need individual assessment.
- Nurse specialist could be important but not all cancer groups have specialist nurses.
- Individual approach – introduce topic at diagnosis – then clinicians decide if the man is ready.
- Not at initial diagnosis – none of us has the answer here – map patient journeys to pick up best point.
- Hospital after treatment to be positive and give hope and confidence.
- Discharge? Part of broader recovery questions and discussion.

### How should men be made aware?

- Online, links from websites and needs to be

accessible on a smartphone.

- Occupational Health/HR departments
- Don't just target men – partners and family too
- Available in treatment clinics
- Hospital/specialist nurses
- Fit for work

### Potential Challenges with implementation and solutions

- How broad this is having to be i.e. suitable for all of Europe? – Start with UK version so can do links with other resources
- How do services get physical copies? – cost of print run – How do we encourage the online resource?
- The varying legislation across the four UK countries.
- Producing something applicable to all cancers – Focus on common problems – fatigue, managing expectations
- Becoming out-dated – put online
- Keeping it short – easily navigated on electronic device
- Terminology manual v toolkit – see PHE work and health toolkits for examples and ideas
- Addressing all working scenarios – web based modules links to appropriate resources.
- Employer knowledge and understanding – employer section particularly on long term effects of treatment
- Male friendly – short, easy read, diagrams
- Making it relevant to all groups of men – culture, ethnic origin, reading age, social class, gay, learning disabilities
- Making employers aware of the manual – awareness campaign for employers
- Getting the manual noticed amongst all the other info – men aren't as likely to read as women – keep it graphic – simple language as per the other manuals in your series.

### Evaluation – when and how

- Need good formative evaluation – stratified groups – socio-demographic groups/different cultures etc.
- End product user feedback
- Pre-pilot – readability/cultural sensitivity etc.
- Pilot – readability/usability/did it make a difference?
- 6/12months – impact assessment – access/choices made/impact/outcomes for individual
- Online tracking of use and feedback from users – online surveys
- Maybe consider pilot in small area to determine impact initially.

- Ask user group e.g. link with The Christie for access
- Evaluate through practitioners – e.g. RCN Public Health Forum/Association of OH Nurse practitioners Facebook page
- Would you recommend this? Link to share document
- Reach of video/social media clip
- Mrs Agatha Lyons, Occupational Health Nurse
- Mrs Naomi McCay, McMillan Cancer Support
- Prof Eilis McCaughan, Professor in Cancer Care, Ulster University
- Ms Ann McMahon, RCN Research and Innovation Manager
- Mr Dave Mundy, Professional Office - Health Sector UNITE
- Prof Ian Peate, Editor of British Journal of Nursing
- Mr Jim Pollard, Editorial & Creative Consultant; Editor of MHF's websites
- Dr Gillian Prue, Management committee of the Men's Health Forum in Ireland (MHFI); Global Action on Men's Health
- Ms Claire Ronald, Vice-chair of the Northern Ireland Committee Irish Congress of Trades Unions Health committee
- Dr Cherith Semple, MacMillan Cancer Nurse Specialist
- Ms Karen Steadman, Work Foundation

## CLOSING REMARKS

Dr Ian Banks closed the meeting by thanking the speakers, participants and organisers, He thanked colleagues from Ulster University for organising the event and for the Royal College of Nursing for hosting.

## ATTENDEES

- Ms Liz Atkinson, Head of Care Services Cancer Focus, Northern Ireland
- Mrs Shirley Baines, Chief Executive, The Burdett Trust For Nursing
- Prof Ian Banks, President of Europeans Men's Health Forum
- Mr Peter Banks, Fandangle Films
- Dame Carol Black, Principal of Newnham College, Cambridge. Advisor to the British Government on the relationship between work and health
- Dr Steve Boorman, Director of Employee Health for Empactis and Honorary Professorial Fellow of the Royal Society of Public Health
- Mr Raymond Bothwell, Patient Advocate
- Mr Brian Conway, Patient Advocate
- Ms Sarah Fry, Representing Daniel Kelly of European Oncology Nursing Society; Royal College of Nursing Chair of Nursing Research, EONS President
- Dr Ali Hashtroudi, Occupational Health Doctor, Occupational Health Department, Guys Hospital, London
- Mr Pat Hamill, Patient Advocate
- Prof Anne Harriss, Professor & Course Director for Occupational Health, London South Bank University
- Ms Sisley Henning, Fandangle Films
- Ms Tracy Herd, Independent Health Improvement Specialist, EMHF
- Ms Helen Kirk, Associate Lead Nurse, Workforce at Public Health England and RCN Public Health Forum member
- Dr Briege M Lagan, Lecturer in Nursing & Public Health, Ulster University
- Ms Isabelle Lebrocquy, Founder of oPuce
- Dr Paul Litchfield, Chief Medical Officer at BT Group

## BIOGRAPHY: CAROL BLACK

Professor Dame Carol Black DBE, FRCP, FMedSci is Principal of Newnham College Cambridge and Expert Adviser on Health and Work to NHS England and Public Health England. She chairs the Board of Think Ahead, the Government's new fast-stream training programme for Mental Health Social Workers, and the RSSB's Health and Wellbeing Policy Group. She is a member of the Welsh Government's Parliamentary Review of Health and Social Care in Wales and Bevan Commission on health in Wales, the board of UK Active, Rand Europe's Council of Advisers, PwC's Health Industries Oversight Board, and the Advisory Board of Step up to Serve.

As Principal of Newnham she is on several committees in Cambridge University, for example the Advisory Board of the Centre for Science and Public Policy, and is one of the Deputy Vice-Chancellors

In November 2011 when National Director for Health and Work she completed as Co-Chair an independent review for the UK Government of sickness absence in Britain. The recommendations of this report are now being put in place, with for example a national Fit for Work Service. She is now finishing a further independent review for the Government, of employment outcomes of addiction to drugs or alcohol, or obesity, and the benefits system.



PHOTO: KATY BLACKWOOD