Cheshire & Merseyside Cancer Alliance

The Cancer Academy

# The Evolution of the Supportive Cancer Workforce

Sharon Rowe Workforce Transformation and Education Lead

Sharon.rowe@nhs.net

NHS Health Education England

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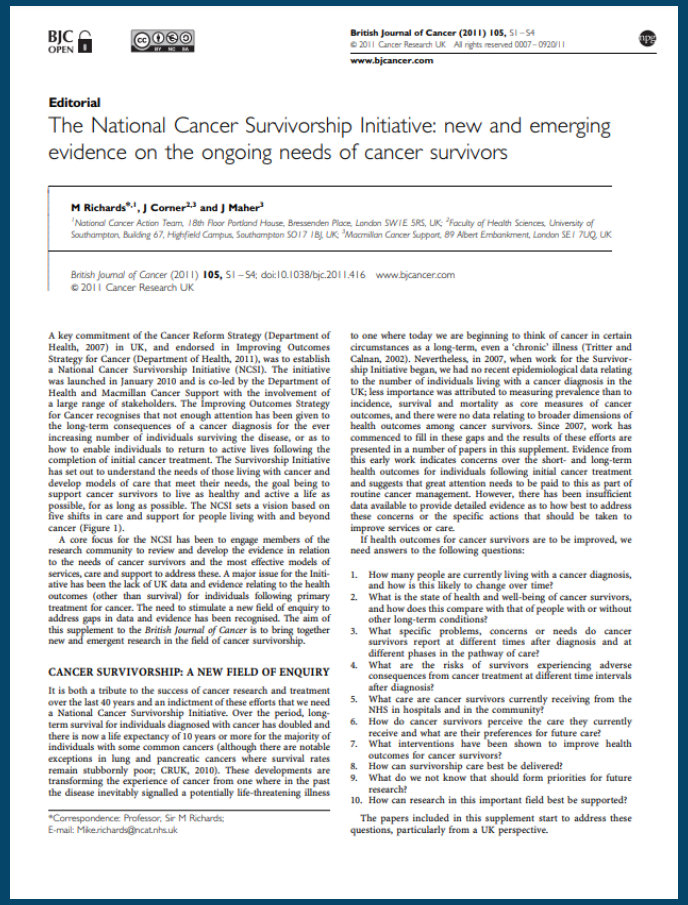
# The changing landscape of cancer…



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**Editorial**

## The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors

M Richards*[,1], J Corner[2,3] and J Maher[3]

[1]National Cancer Action Team, 18th Floor Portland House, Bressenden Place, London SW1E 5RS, UK; [2]Faculty of Health Sciences, University of Southampton, Building 67, Highfield Campus, Southampton SO17 1BJ, UK; [3]Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ, UK

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A key commitment of the Cancer Reform Strategy (Department of Health, 2007) in UK, and endorsed in Improving Outcomes Strategy for Cancer (Department of Health, 2011), was to establish a National Cancer Survivorship Initiative (NCSI). The initiative was launched in January 2010 and is co-led by the Department of Health and Macmillan Cancer Support with the involvement of a large range of stakeholders. The Improving Outcomes Strategy for Cancer recognises that not enough attention has been given to the long-term consequences of a cancer diagnosis for the ever increasing number of individuals surviving the disease, or as to how to enable individuals to return to active lives following the completion of initial cancer treatment. The Survivorship Initiative has set out to understand the needs of those living with cancer and develop models of care that meet their needs, the goal being to support cancer survivors to live as healthy and active a life as possible, for as long as possible. The NCSI sets a vision based on five shifts in care and support for people living with and beyond cancer (Figure 1).

A core focus for the NCSI has been to engage members of the research community to review and develop the evidence in relation to the needs of cancer survivors and the most effective models of services, care and support to address these. A major issue for the Initiative has been the lack of UK data and evidence relating to the health outcomes (other than survival) for individuals following primary treatment for cancer. The need to stimulate a new field of enquiry to address gaps in data and evidence has been recognised. The aims of this supplement to the *British Journal of Cancer* is to bring together new and emergent research in the field of cancer survivorship.

### CANCER SURVIVORSHIP: A NEW FIELD OF ENQUIRY

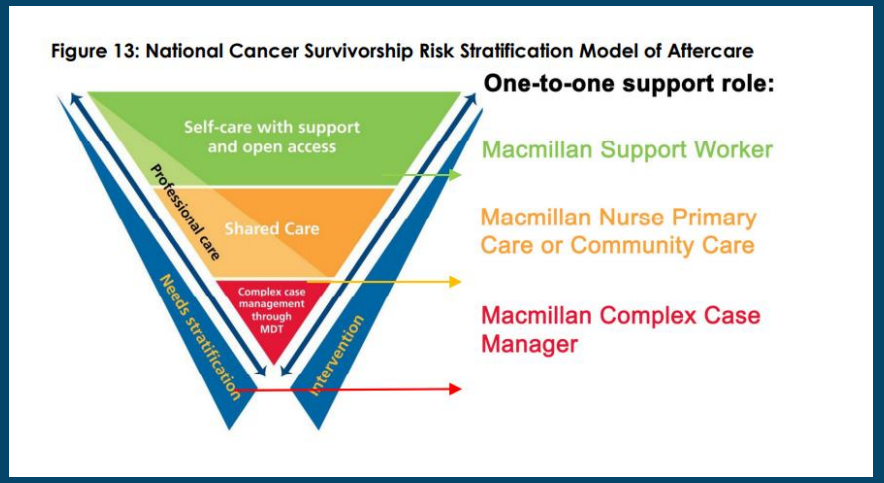
It is both a tribute to the success of cancer research and treatment over the last 40 years and an indictment of these efforts that we need a National Cancer Survivorship Initiative. Over the period, long-term survival for individuals diagnosed with cancer has doubled and there is now a life expectancy of 10 years or more for the majority of individuals with some common cancers (although there are notable exceptions in lung and pancreatic cancers where survival rates remain stubbornly poor; CRUK, 2010). These developments are transforming the experience of cancer from one where in the past the disease inevitably signalled a potentially life-threatening illness to one where today we are beginning to think of cancer in certain circumstances as a long-term, even a 'chronic' illness (Tritter and Calnan, 2002). Nevertheless, in 2007, when work for the Survivorship Initiative began, we had no recent epidemiological data relating to the number of individuals living with a cancer diagnosis in the UK; less importance was attributed to measuring prevalence than to incidence, survival and mortality as core measures of cancer outcomes, and there were no data relating to broader dimensions of health outcomes among cancer survivors. Since 2007, work has commenced to fill in these gaps and the results of these efforts are presented in a number of papers in this supplement. Evidence from this early work indicates concerns over the short- and long-term health outcomes for individuals following initial cancer treatment and suggests that great attention needs to be paid to this as part of routine cancer management. However, there has been insufficient data available to provide detailed evidence as to how best to address these concerns or the specific actions that should be taken to improve services or care.

If health outcomes for cancer survivors are to be improved, we need answers to the following questions:

1. How many people are currently living with a cancer diagnosis, and how is this likely to change over time?
2. What is the state of health and well-being of cancer survivors, and how does this compare with that of people with or without other long-term conditions?
3. What specific problems, concerns or needs do cancer survivors report at different times after diagnosis and at different phases in the pathway of care?
4. What are the risks of survivors experiencing adverse consequences from cancer treatment at different time intervals after diagnosis?
5. What care are cancer survivors currently receiving from the NHS in hospitals and in the community?
6. How do cancer survivors perceive the care they currently receive and what are their preferences for future care?
7. What interventions have been shown to improve health outcomes for cancer survivors?
8. How can survivorship care best be delivered?
9. What do we not know that should form priorities for future research?
10. How can research in this important field best be supported?

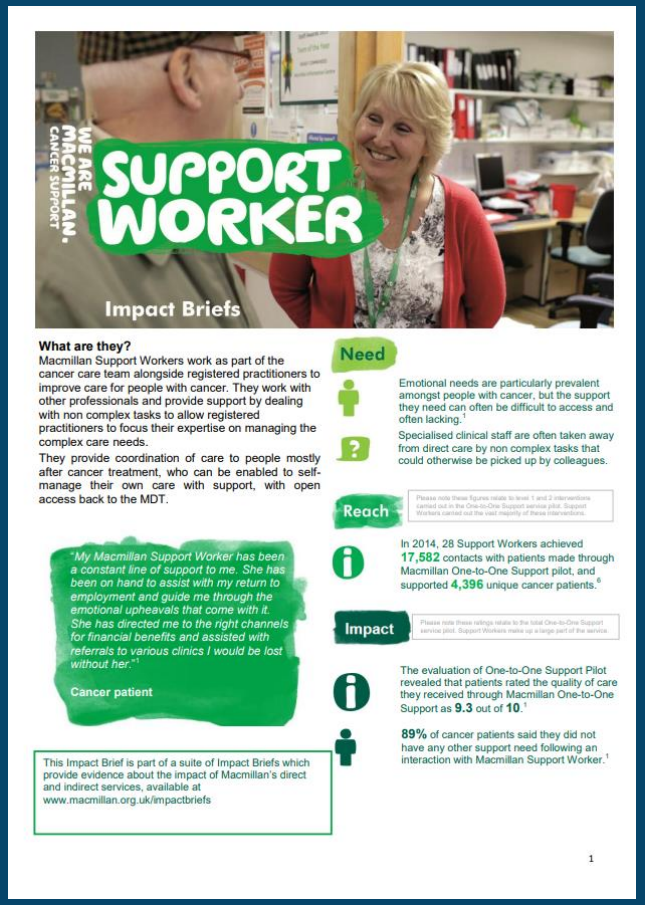
The papers included in this supplement start to address these questions, particularly from a UK perspective.

*Correspondence: Professor, Sir M Richards;
E-mail: Mike.richards@ncat.nhs.uk




Macmillan Support Worker:

- supervised by registered practitioner within an existing team in health or social care
- coordinate care by providing a single point of access into the service, helping people to navigate the system
- coordinate care for people with non-complex care needs
- coordinate education and support for people with non-complex care needs






**What are they?**

Macmillan Support Workers work as part of the cancer care team alongside registered practitioners to improve care for people with cancer. They work with other professionals and provide support by dealing with non complex tasks to allow registered practitioners to focus their expertise on managing the complex care needs.

They provide coordination of care to people mostly after cancer treatment, who can be enabled to self-manage their own care with support, with open access back to the MDT.

*"My Macmillan Support Worker has been a constant line of support to me. She has been on hand to assist with my return to employment and guide me through the emotional upheavals that come with it. She has directed me to the right channels for financial benefits and assisted with referrals to various clinics I would be lost without her."*[1]

Cancer patient

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan's direct and indirect services, available at www.macmillan.org.uk/impactbriefs

**Need**

Emotional needs are particularly prevalent amongst people with cancer, but the support they need can often be difficult to access and often lacking.[1]

Specialised clinical staff are often taken away from direct care by non complex tasks that could otherwise be picked up by colleagues.

**Reach**

Please note these figures relate to level 1 and 2 interventions carried out in the One-to-One Support service pilot. Support Workers carried out the vast majority of these interventions.

In 2014, 28 Support Workers achieved **17,582** contacts with patients made through Macmillan One-to-One Support pilot, and supported **4,396** unique cancer patients.[6]

**Impact**

Please note these ratings relate to the total One-to-One Support service pilot. Support Workers make up a large part of the service.

The evaluation of One-to-One Support Pilot revealed that patients rated the quality of care they received through Macmillan One-to-One Support as **9.3** out of **10**.[1]

**89%** of cancer patients said they did not have any other support need following an interaction with Macmillan Support Worker.[1]

1

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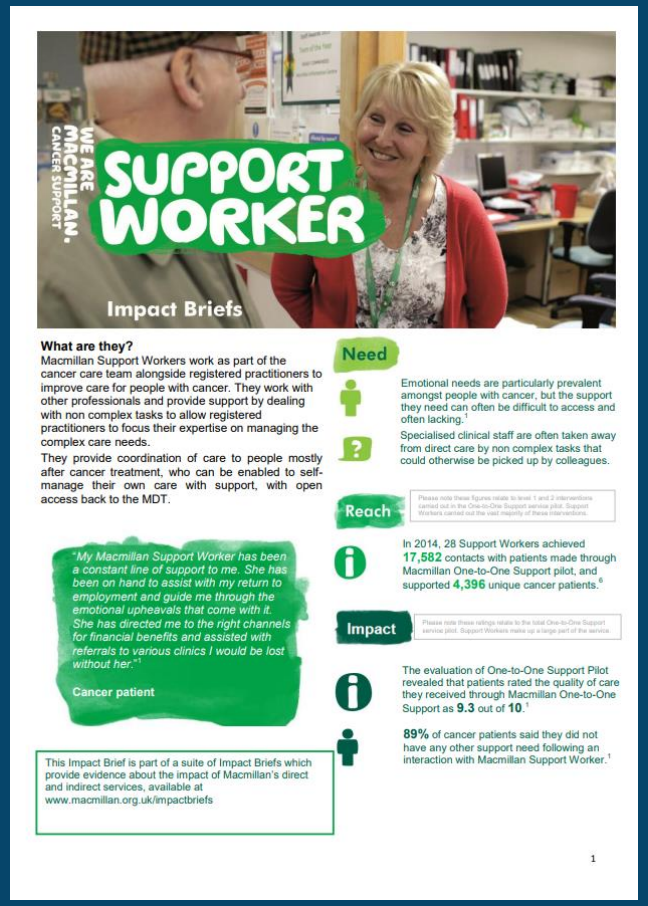


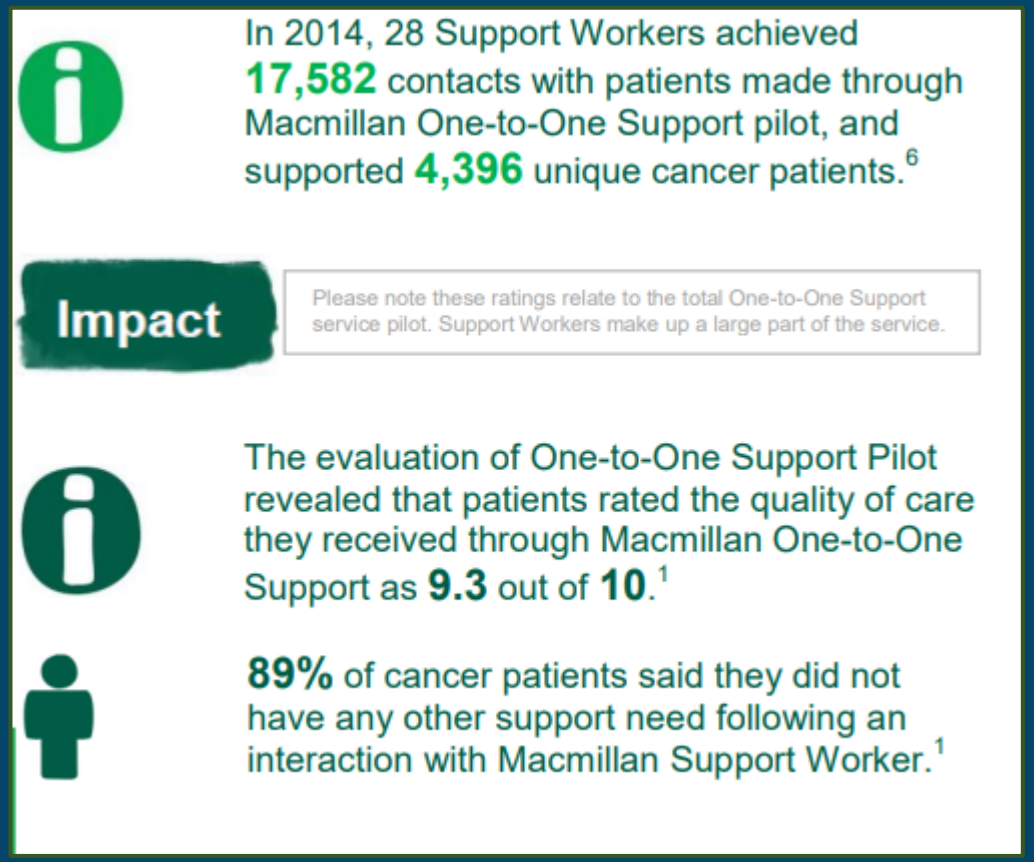

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# The story in Cheshire and Merseyside…

Investment from Macmillan's LWBC Programme  2014 – 2017

Funding continued by CMCA to date

2016 Development Programme

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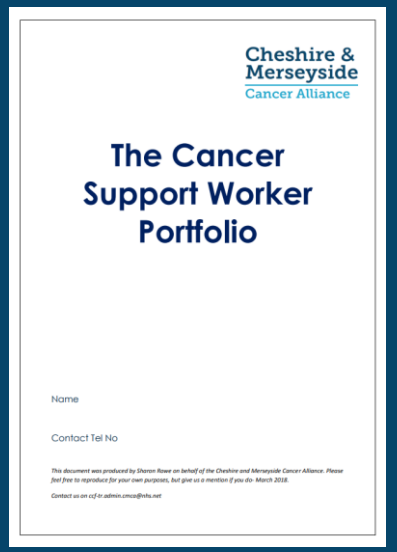
# The story in Cheshire and Merseyside…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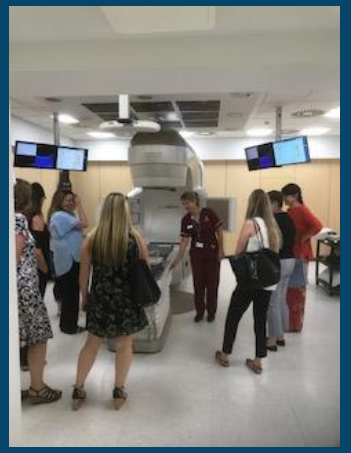
The Cancer Support Worker Portfolio

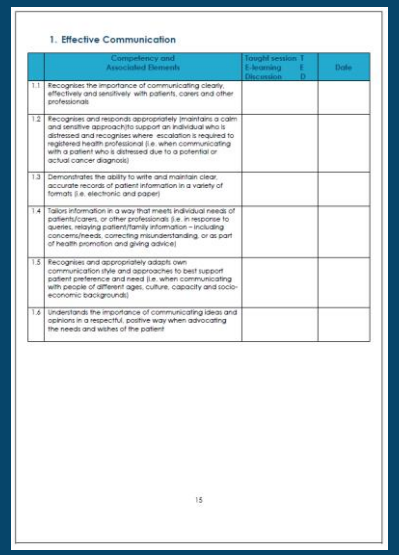
Name

Contact Tel No

*This document was produced by Sharon Rowe on behalf of the Cheshire and Merseyside Cancer Alliance. Please feel free to reproduce for your own purposes, but give us a mention if you do- March 2018.*

*Contact us on ccf-tr-admin.cmca@nhs.net*




1. Effective Communication

| | Competency and Associated Elements | Taught session T E-learning E Discussion D | Date |
|---|---|---|---|
| 1.1 | Recognises the importance of communicating clearly, effectively and sensitively with patients, carers and other professionals | | |
| 1.2 | Recognises and responds appropriately (maintains a calm and sensitive approach)to support an individual who is distressed and recognises where escalation is required to registered health professional (i.e. when communicating with a patient who is distressed due to a potential or actual cancer diagnosis) | | |
| 1.3 | Demonstrates the ability to write and maintain clear, accurate records of patient information in a variety of formats (i.e. electronic and paper) | | |
| 1.4 | Tailors information in a way that meets individual needs of patients/carers, or other professionals (i.e. in response to queries, relaying patient/family information – including concerns/needs, correcting misunderstanding, or as part of health promotion and giving advice) | | |
| 1.5 | Recognises and appropriately adapts own communication style and approaches to best support patient preference and need (i.e. when communicating with people of different ages, culture, capacity and socio-economic backgrounds) | | |
| 1.6 | Understands the importance of communicating ideas and opinions in a respectful, positive way when advocating the needs and wishes of the patient | | |

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Investment from Macmillan's LWBC Programme 2014 – 2017

Funding continued by CMCA to date

2016 introduced Development

Programme and Portfolio referenced from national guidelines

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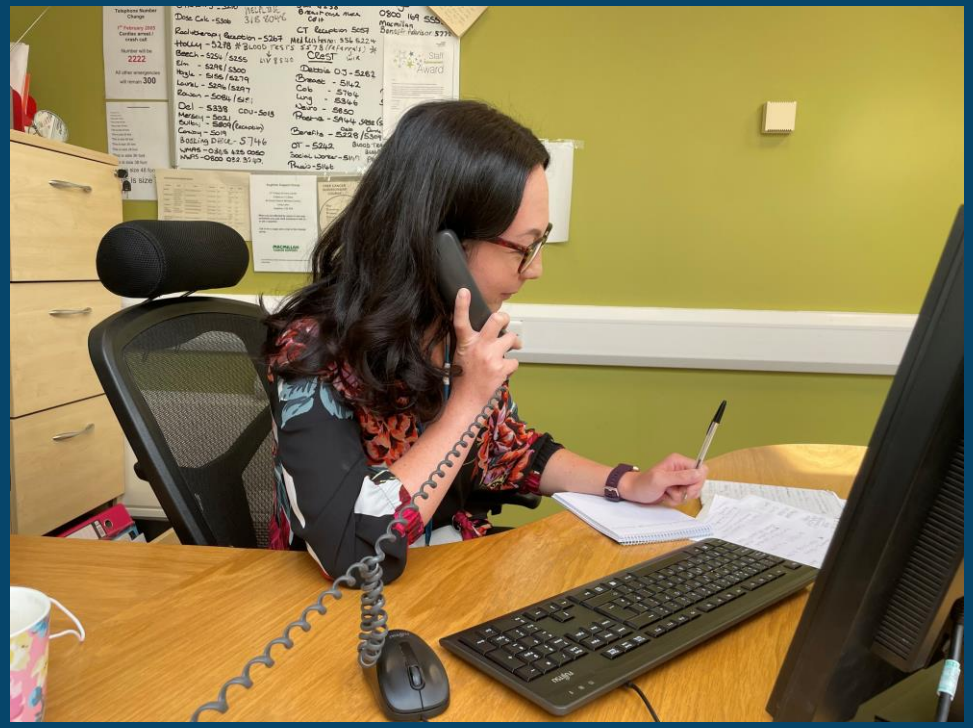
# The story in Cheshire and Merseyside…



Investment from Macmillan's LWBC Programme  2014 – 2017

Funding continued by CMCA to date

2016 introduced Development

Programme and Portfolio referenced from national guidelines

Expansion of roles into Early Diagnosis and Primary /Community Care

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# Developing a supportive cancer workforce

Cancer Navigators

Cancer Support Workers

Cancer Care Co-ordinators

?

Facilitates investigations through to diagnostic resolution (MECC)

Offers personalised care and support planning during treatment

Facilitates self supported management through remote portal.
HWB workshops

Within Primary /Community care liaises with secondary care
Screening
PC&SP + CCR

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# Developing a supportive cancer workforce

| Cancer Navigators | Cancer Support Workers | Cancer care Co-ordinators | ? |
|---|---|---|---|

| Facilitates investigations through to diagnostic resolution (MECC) | Offers personalised care and support planning during treatment | Facilitates self supported management through remote portal.<br>HWB workshops | Within Primary /Community care liaises with secondary care<br>Screening<br>PC&SP + CCR |
|---|---|---|---|

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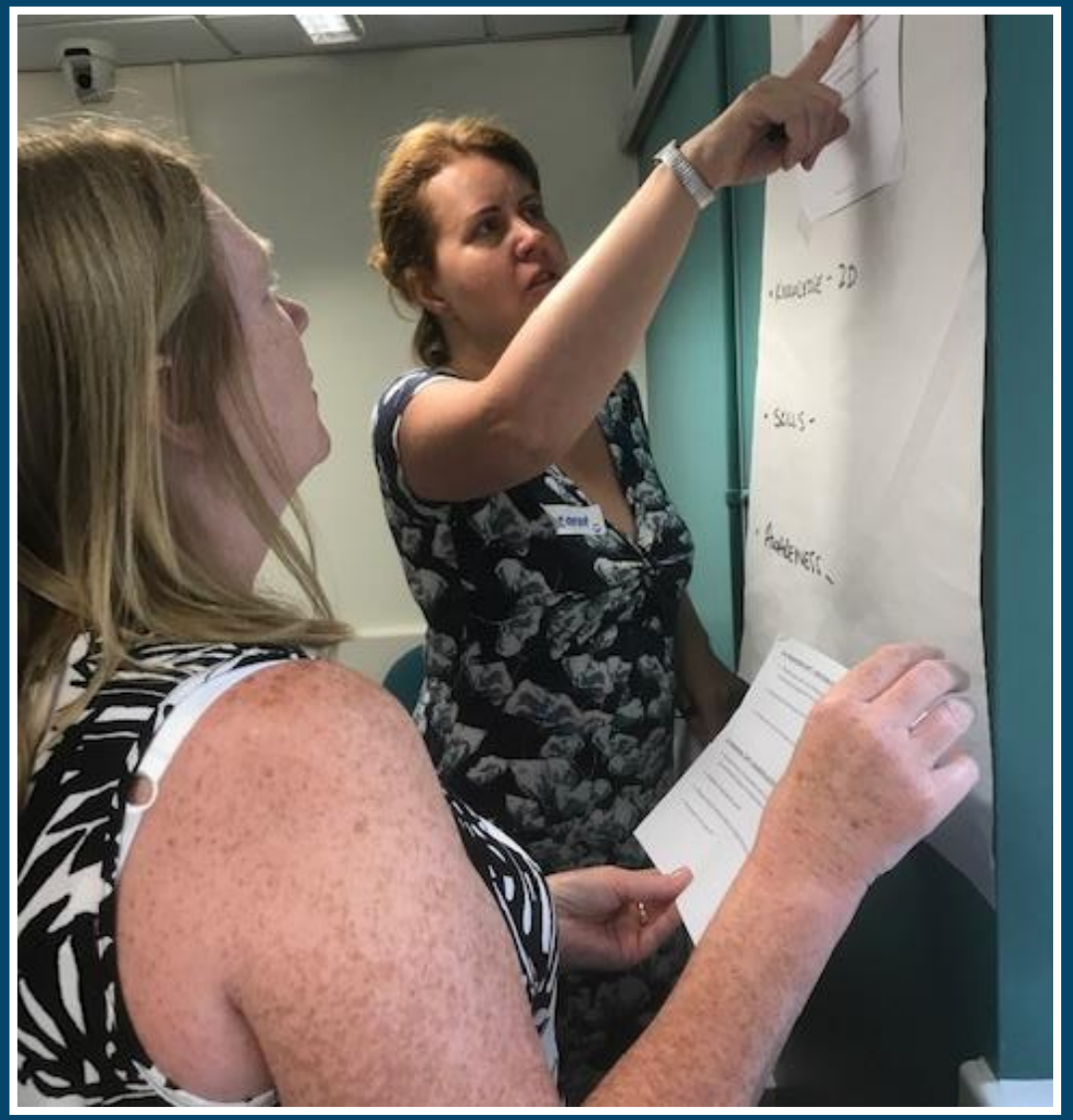
Education programme in C&M since 2016
>200 supportive cancer care staff attended
2021 - Virtual Principles of Cancer Care Programme developed



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# PCCP Syllabus

| DAY 1 | DAY 2 | DAY 3 | DAY 4 |
|---|---|---|---|
| Introduction to virtual working and digital skills<br>Working Agreements<br>Getting acquainted and understanding job roles and differences within the cancer workforce<br>Professional accountability, the law and ethical decision making<br>The ACCEND programme and implications for the supportive cancer care programme<br>Philosophy and principles of cancer care<br>Biological basis/Process of carcinogenesis<br>Genomics and its applications in cancer diagnosis, prognosis, and treatment<br>Grading and staging cancer<br>Cancer treatments and decision-making<br>Risk reduction, screening<br>Health inequalities in cancer care | Models of communication, supportive conversations, emotional intelligence, wellbeing<br><br>Discussing the barriers to compassionate communication<br><br>Practice facilitative communication skills in a safe and supportive environment<br><br>Identify transferable communication strategies for difficult situations such as handling distress or anger, end of life conversations, difficult questions and information giving.<br><br>Practice different techniques to communicate in person, by telephone or virtually. | Linking this training with Personalised care and Support Planning (HNA)<br>Increase awareness of psychological processes of adjustment and loss, and the impact of this on patients and their supporters.<br>Refresh knowledge of communication skills, including use of open questions, affirmations, reflections, and summaries; Introduce OARS model of listening (Practical using Case Studies)<br>Introduction to ACT<br>Develop awareness of the 'choice point' assessment framework to identify what's important to the patient (their values) and how the patient's psychological concerns may impact this.<br>Screening for psychological needs (Activity)<br>Mindfulness | Crisis intervention. What to say, duty of care and escalation<br><br>Using Acceptance and Commitment Theory as a low-level intervention (Activity)<br><br>Challenges of the role(s) (Activity)<br><br>Open session<br><br>Compassion fatigue and vicarious trauma<br><br>Self-care<br>Mindfulness<br><br>Debrief<br><br>Closure of Course |

ACCEND SUPPORTIVE AND ASSISTIVE CiPs

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# What did you enjoy most about the day?

‘Learning about cancer and how it develops. Really enjoyed the inequality session as well as learning about screening programmes and new ways of testing for cancers. The whole day has been really beneficial overall.’

‘Learning in depth about cancer/staging etc. Feeling like I have some knowledge to back my conversations.’

‘The whole day has been really interesting, informative, easy to follow, engaging and relaxed.’

‘I loved the interaction from different staff joining to help us understand their stories and experience as they have all been different. I loved the cancer webinar as that is basic understanding, we all need to know.’

‘Being able to share our roles with one another and receive and give advice.’’

‘Informative and interesting without being formal.’

‘I really enjoyed everything. I thought it was well thought out and delivered perfectly. I found the talk on staging and grading etc. very informative and feel much more confident.’

Introduction to virtual working and digital skills
Working Agreements
Getting acquainted and understanding job roles and differences within the cancer workforce

Professional accountability, the law and ethical decision making

The ACCEND programme and implications for the supportive cancer care programme

Philosophy and principles of cancer care

Biological basis/Process of carcinogenesis

Genomics and its applications in cancer diagnosis, prognosis, and treatment

Grading and staging cancer

Cancer treatments and decision-making

Risk reduction, screening

Health inequalities in cancer care

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# What was the most helpful part of the training…?

‘All was very useful, relevant and applicable! Was great to have a break-down of how to approach situations using communication skills and then thinking from the psychological skills.’

‘The quality, timescales and breakdown of all aspects aided me to fully understand and also retain what we have been discussing. Delivered in a relaxed and enjoyable way, very approachable tutors. Kept me interested and motivated throughout.’

‘Group discussions and the role plays done by Sharon and Nicola. They were professional at all times and very informative. They validated our opinions and thoughts and I now feel more confident in my ability to speak up.’

‘Psychological skills training as this is something not offered in our trust readily so I am very pleased with it. It has given me a better understanding in-terms of responses to patients’ emotional and psychological concerns.’

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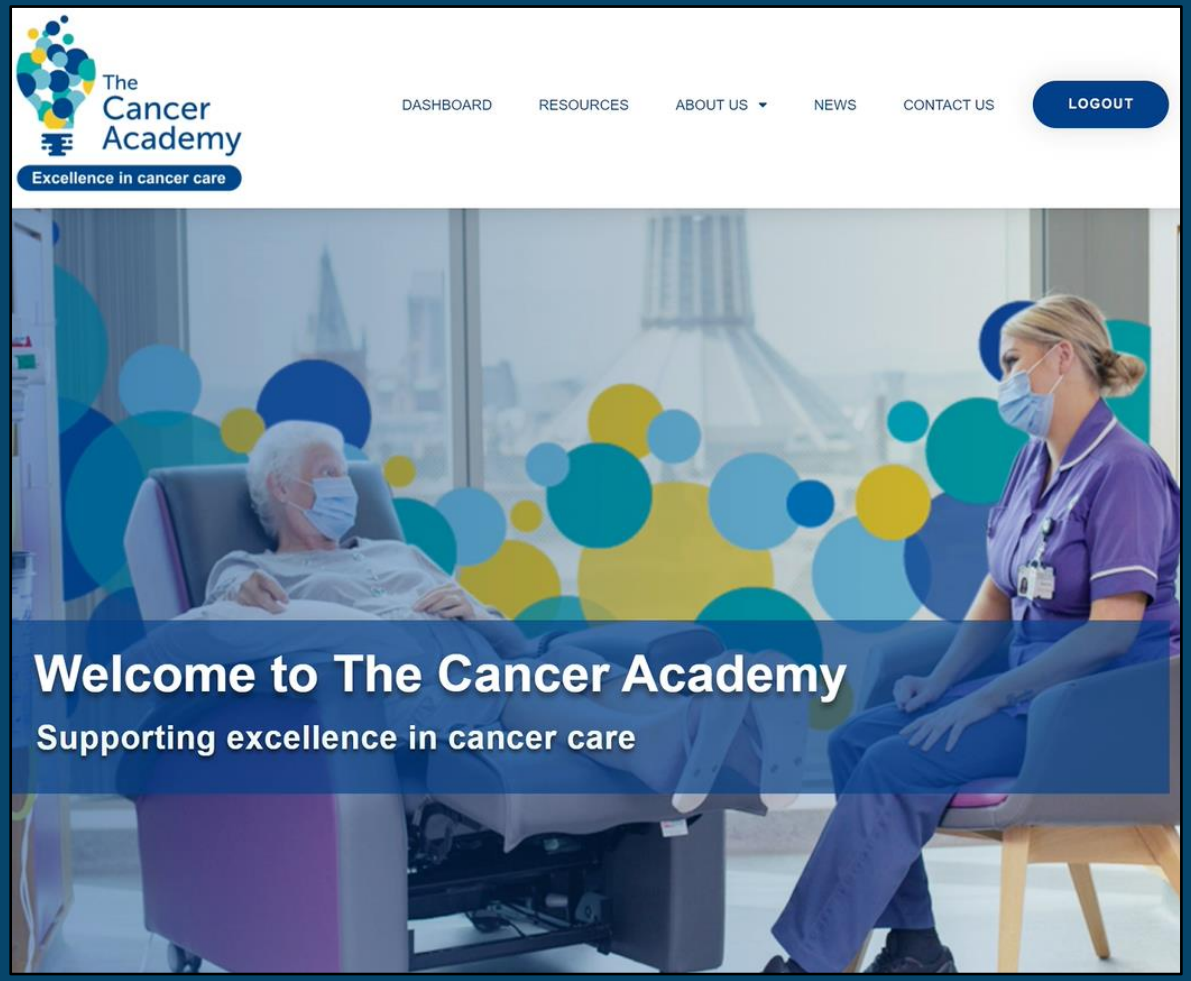


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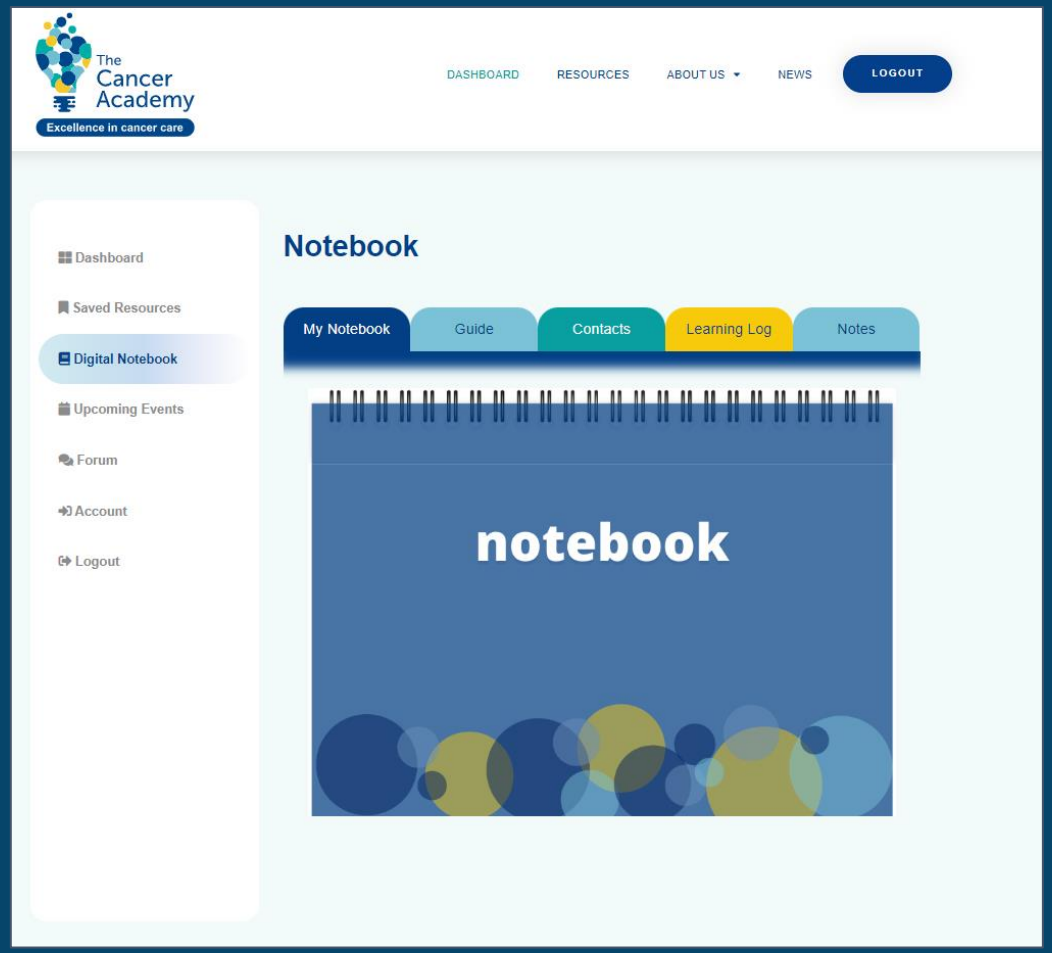

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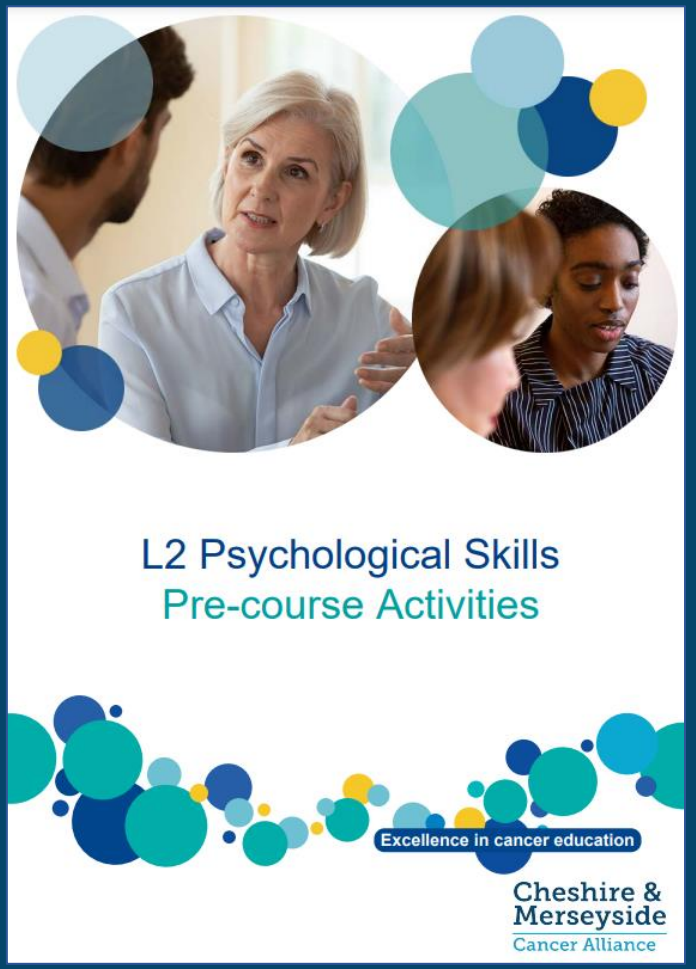
# Principles of Cancer Care Programme

HEE have funded 6 courses (84 places) during 2023. Initially this is available to all Cancer Support Workers, Cancer Navigators and Cancer Care Coordinators. Alliances have been allocated places proportionally and potential applicants should contact their Cancer Alliance Workforce Leads.

Course dates;
23rd-24th & 27th-28th February
16th-17th & 20th 21st March
18th-19th & 22nd & 23rd May
29-30th June & 3rd-4th July
14th-15th & 18th-19th September
28th-29th Septemer & 2nd-3rd October

Applicants are required to complete all 4 days of the course, should have the support of their manager and be able to access supervision within their organisation (if available).

Cancer Alliance Workforce Leads/Managers can complete the application form here. Please complete one form per Alliance. Delegates will then be contacted to arrange a suitable date to attend.



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ACCEND SUPPORTIVE AND ASSISTIVE CiPs

Health Education England

# ACCEND

## Aspirant Cancer Career and Education Development Programme

## Addressing the professional and educational issues for the cancer nursing and allied health professions workforce: A collaborative, strategic, UK-wide approach

**Sharon Rowe Workforce Transformation & Education Lead CMCA**

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ACCEND is a multi year funded programme (2022 – 2025)

Providing end-to-end transformational reform in the education, training and career pathways for **cancer support workers**, nurses and allied health professional's supporting people affected by cancer both now and in the future.

NHS Health Education England

Cheshire & Merseyside Cancer Alliance

Greater Manchester Cancer

Guy's Cancer Academy

MACMILLAN CANCER SUPPORT

UKONS Oncology Nursing Society

UWE Bristol University of the West of England

# ACCEND Supportive & Assitive Hub

NHS
Health Education England

## I am new to cancer (E-Learning)

- **Foundations of Cancer Care** 9 sessions (ELFH)
- **Care Certificate** 15 standards of care (ELFH)

## I wish to enhance my knowledge (E-Learning)

- **Essentials of Cancer Care** includes Biology of Cancer (HEE funded developed by Guys Academy)
- **Personalised Care Planning for people with Cancer** (Macmillan funded hosted Guys Academy)

## I wish to enhance my knowledge (Training Programme)

- **The Principles of Cancer Care Programme**
- **Core** training for the assistive & supportive workforce
- Virtual programme over 4 days (Max 14 in each session)

## I wish to progress in my career (Qualification)

- **Evidencing Work Based Learning**
- Free for all Macmillan staff - application process
- University Application & Academic qualification

## I wish to learn in my own time

- **Cancer related e-learning resources**
- **More** training
- **Supporting you to support others**
- **Other long term conditions**

elfh
elearning for healthcare

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# Going forward:

38 PCCP live virtual sessions over 18 months (Oct 23-March 25), training 532 members of our cancer supportive workforce across England.

12 sessions will run between Oct 23 - March 24 and 26 sessions during 2024/2025.

Discussions in progress regarding accreditation

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*‘The whole training package was excellent; it included all the relevant tools for my role. I am taking away a new box of skills and confidence and feel I know my role better than when I started the training. The course came together well, and the tutors were exceptional.’*