



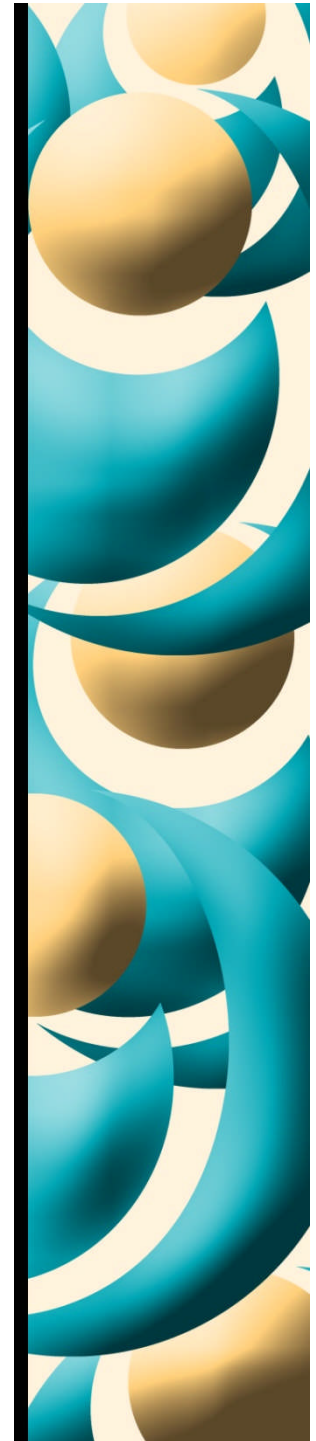
# **Welcome to the** Inaugural meeting of the **UKONS Living With and Beyond Cancer Forum**



Roche Products Ltd is a  
'Platinum Partner' of UKONS



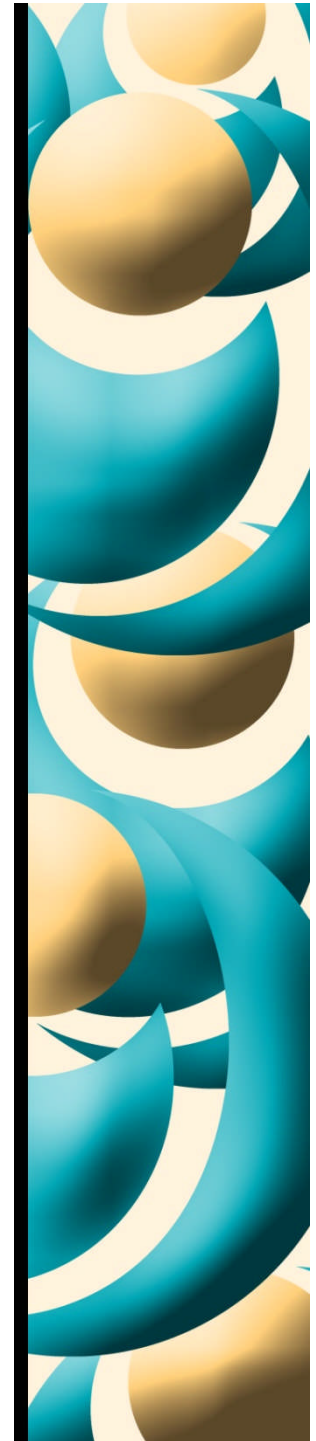
Merck Sharp and Dohme is a  
'Bronze Partner' of UKONS





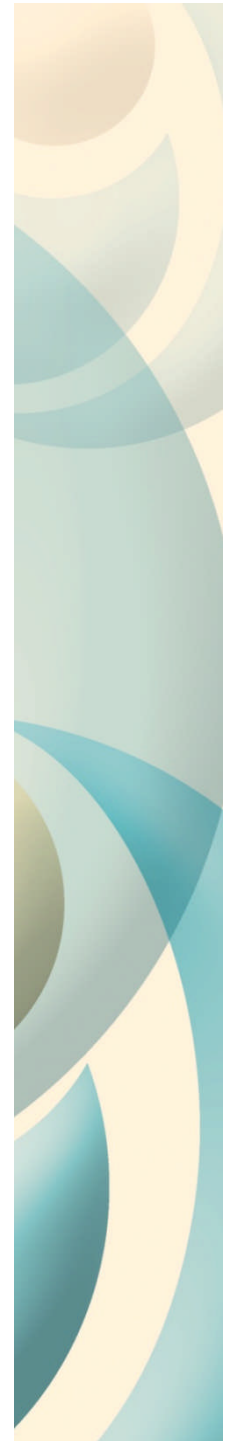
# Welcome

Cheryl Vidall  
President Elect UKONS  
Clinical Risk and Practice Development Manager  
Healthcare at Home



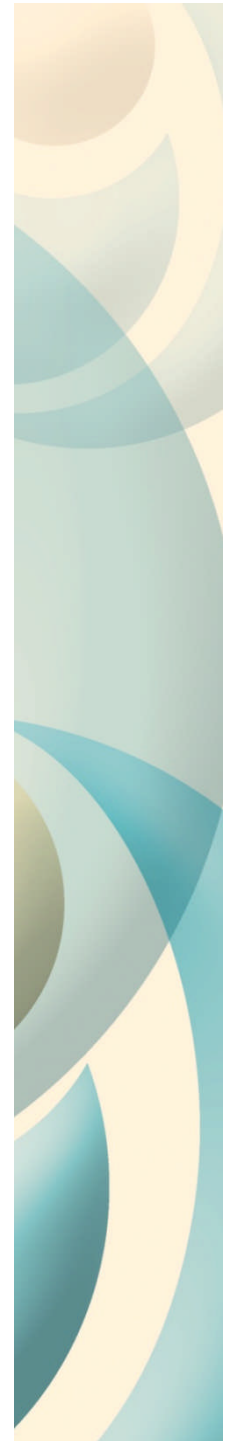
# Housekeeping

- Fire alarms
- Mobile phones
- Breaks
- Evaluation



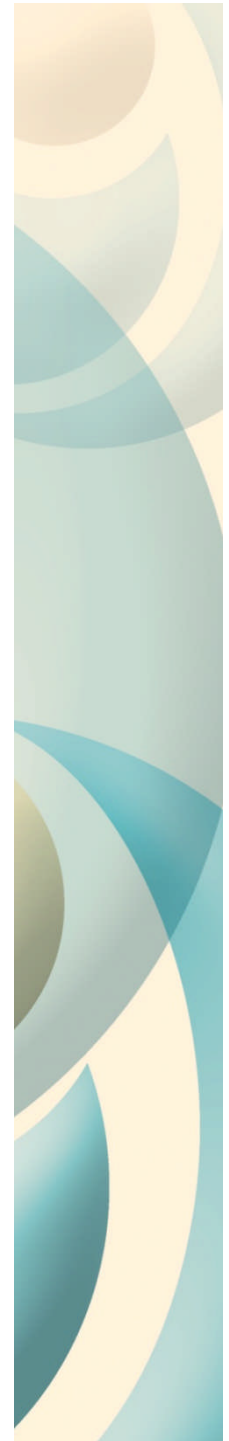
# Background

- Cancer Reform Strategy, chapter 5 - 'Living with and beyond cancer'
- Cancer is becoming a long-term condition
- Focus on supporting patients beyond acute treatment
- UKONS leading the way by addressing the subject through this new forum



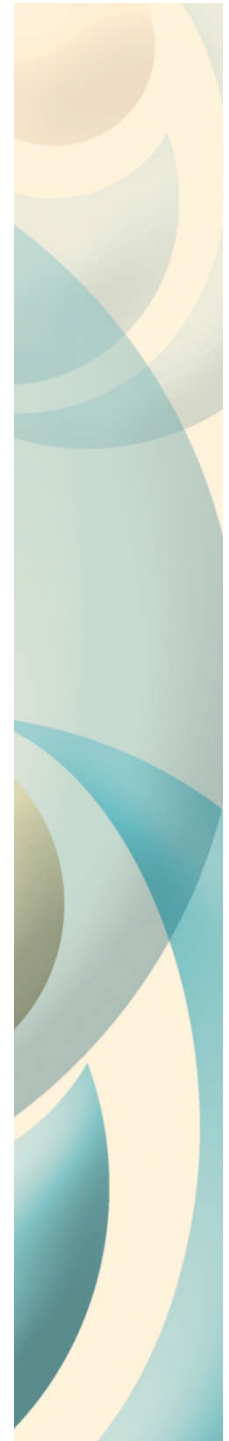
# Other UKONS work

- Chemotherapy forum – established Sept 2007
  - 9 regional groups with a chair and vice chairs
  - Rapid response from all forum members to questions posted – hot topics
  - Leading on key oncology work and cascading the learning
- Genetics Forum – being launched in Oct
- Website
- Newsletter
- Scholarships
- Annual Conference



# Special thanks

- Natalie Doyle
- Debbie Fenlon
- Sally Campalani
- Beryl Roberts
  
- Succinct – Catherine, Lisa, Liz
- Speakers
- Delegates



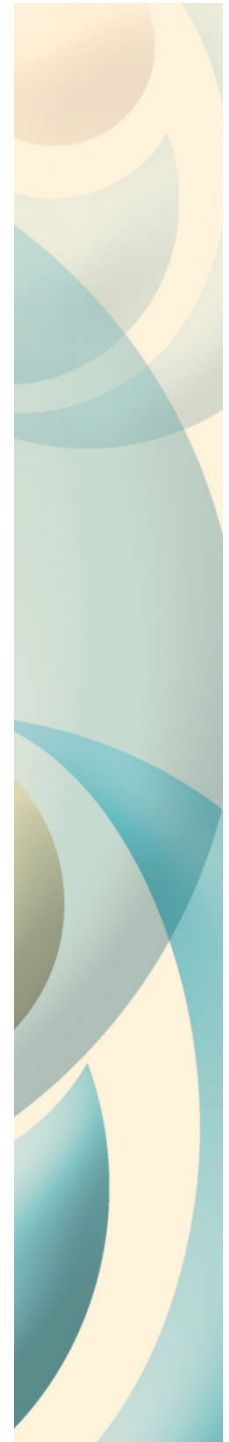
# Opening remarks and meeting introduction

## **Natalie Doyle**

Nurse Consultant, Cancer Rehabilitation,  
The Royal Marsden Hospital

## **Debbie Fenlon**

Senior Research Fellow,  
University of Southampton



# Living With and Beyond Cancer Forum Opening Remarks

Natalie Doyle  
Nurse Consultant, Cancer  
Rehabilitation  
Royal Marsden NHS Foundation Trust  
[natalie.doyle@rmh.nhs.uk](mailto:natalie.doyle@rmh.nhs.uk)



## WE CAN NO LONGER....

- “ SAVE PEOPLE FROM DROWNING...(AND THEN)...LEAVE THEM ON THE DOCK TO COUGH AND SPLUTTER ON THEIR OWN IN THE BELIEF WE HAVE DONE ALL WE CAN”

(MULLAN 1985 P 273)



# MACMILLAN WORKING DEFINITION OF SURVIVORSHIP

- A CANCER SURVIVOR IS SOMEONE WHO IS LIVING WITH CANCER OR WHO HAS HAD CANCER.
- THERE ARE CURRENTLY 2 MILLION SUCH PEOPLE IN THE UK.
- OUR WORKING DEFINITION: FROM THE END OF ACTIVE TREATMENT UNTIL END OF LIFE CARE



# SEMANTICS

- SURVIVORSHIP
- AMERICANISMS
- CANCER REFORM STRATEGY
- CHAPTER 5



# CANCER SURVIVORSHIP

- **CANCER SURVIVORSHIP IS A PROCESS BEGINNING ON DIAGNOSIS INVOLVING UNCERTAINTY. IT IS A LIFE CHANGING EXPERIENCE, WITH DUALITY OF POSITIVE AND NEGATIVE ASPECTS, UNIQUE TO THE INDIVIDUAL BUT WITH SOME UNIVERSALITY.**

(DOYLE 2008)



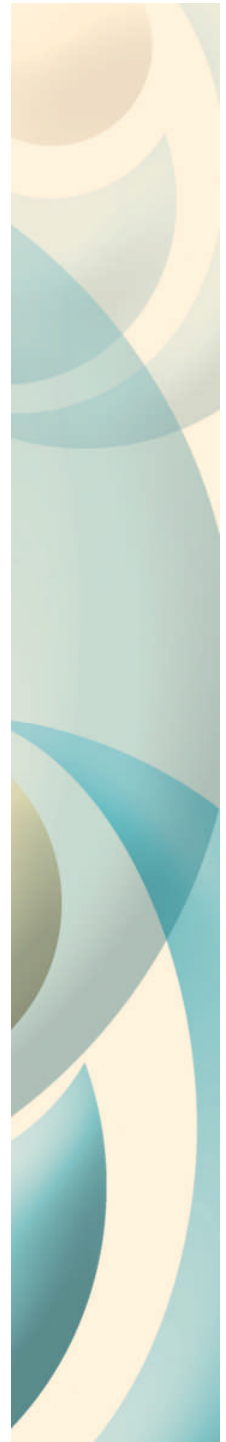
# ATTRIBUTES

1. PROCESS
2. UNCERTAINTY
3. LIFE CHANGING EXPERIENCE
4. DUALITY OF POSITIVE & NEGATIVE ASPECTS
5. INDIVIDUAL EXPERIENCE WITH UNIVERSALITY
6. TALK OF THE CANCER CENTRE



**THE KEY**

**LIVING WITH  
UNCERTAINTY**



# CANCER REFORM STRATEGY

## CHAPTER 5

- IMPLEMENTATION OF NICE GUIDANCE
- INFORMATION PRESCRIPTIONS
- FACE TO FACE COMMUNICATION TRAINING
- PATIENT INVOLVEMENT IN DECISION MAKING
- ROLE OF THE CNS
- CANCER SURVIVORSHIP INITIATIVE
- PATIENT EXPERIENCE SURVEYS



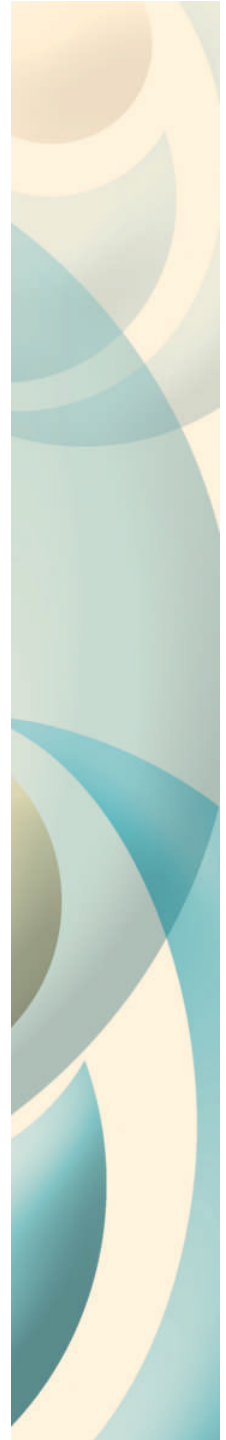
# THE KEY

- **THE ROLE OF THE NURSE**



- **PATIENT CARE DOES NOT END WHEN TREATMENT ENDS**

(STOVALL 2006)



**THE KEY**

**WHO TAKES**

**RESPONSIBILITY**

**?**



# NURSES AS ENTREPRENEURS

- NURSING FOR THE 21<sup>ST</sup> CENTURY
- CARE BY EMPOWERMENT
- TEACHABLE MOMENT
- SELF-MANAGEMENT
- CHRONIC DISEASE MANAGEMENT
- PARTNERSHIP NURSING
- MULTI-PROFESSIONAL WORKING



IT TAKES CHUTZPAH  
KNOWING IS NOT  
ENOUGH;  
WE MUST APPLY.  
WILLING IS NOT ENOUGH;  
WE MUST DO.

(GOETHE)



# Living With and Beyond Cancer Forum Opening Remarks

Deborah Fenlon  
Senior Research Fellow,  
Macmillan Research Unit,  
University of Southampton  
[dfenlon@soton.ac.uk](mailto:dfenlon@soton.ac.uk)



# Agenda for the day

- Presentations am
- Workshops pm



# Workshops

- Programmes of care
- Supportive resources
- Hard to reach groups
- Survivorship care plans
- Training of health professionals
- Key worker role
- Evaluation and research



# Workshops

- What are the 3 highest priorities for action?
- What is the main challenge to action?
- How might this challenge be addressed?

