

Getting your House in Order



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Advance Care Planning

35th Norfolk Palliative Care Conference



8th May 2024, John Innes Conference Centre, Colney Lane, Norwich, NR4 7UY

35th NORFOLK PALLIATIVE CARE CONFERENCE

John Innes Conference Centre, Colney Lane, Norwich, NR4 7UH

Chairperson - Daniela Ayre

08.30 Coffee and Registration

09.15 Welcome

09.30 'Hope for the best plan for the rest. The Waiting Room Revolution'

Dr. Samantha Winemaker, Associate Clinical Professor, McMaster University, Dr. Hsien Seow, Professor, McMaster University, bestselling authors.

10.20 'You Make a difference (intelligent kindness)' Tommy Whitelaw, National Lead Person Centred Voices, Alliance Scotland.

11-11.45 Coffee

11.45 'What you do want? Planning for the future: why it matters and where to start.'

Zoe Harris, CEO, My Care Matters.

12.20 'What do you not want to happen? Advance Decisions and how they help'

Usha Grieve, Director of Partnerships and service, Compassion in dying.

12.55 'Ethical and Policy Dilemmas in (DNA)CPR Decisions: Results from the Autonomy Project Audit' Wayne Martin, Professor of Philosophy, The Autonomy Project, University of Essex.

13.25-14.25 Lunch & Networking

14.25 'Who would speak for you' Clare Fuller, Advance Care Planning Advocate, Educator & Coach and LPA Consultant- Speak For Me.

14.55 'Getting your digital life in order' James Norris Founder of My Wishes & The Digital Legacy Association.

15.30 'Advance Care Planning Journeys, Q&A Panel' Suzie Taylor patient, Dr Louise Grant Palliative Consultant NNUHFT, Dani Ayre SPCN NNUHFT, Clare Fuller Advance Care Planning Advocate, Educator & Coach and LPA Consultant - Speak For Me and Chaired by Sammy Winemaker Associate Clinical Professor, McMaster University Wellbeing Practitioner, NNUH.

16.15 Close (Times and speakers may be subject to change)



Dr. Samantha Winemaker

Associate Clinical Professor,
McMaster University

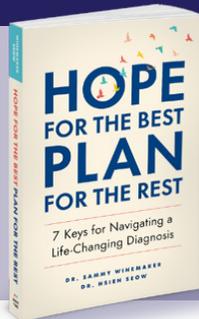
Dr. Hsien Seow

Professor, McMaster University



Title of talk:

'Hope for the best, plan for the rest. The Waiting Room Revolution'



Bio:

Dr. Sammy Winemaker is a palliative care physician who cares for patients with serious illness and their families in their homes. She is an Associate Clinical Professor at McMaster University in the Department of Family Medicine, Division of Palliative Care. She has won numerous awards for her leadership and palliative care education for health care professionals.

Dr. Hsien Seow is the Canada Research Chair in Palliative Care and Health System Innovation and a Professor in the Department of Oncology, McMaster University. He publishes health care and policy research focused on improving care for patients with serious illness.

They are authors of Hope for the Best, Plan for the Rest: 7 Keys for Navigating a Life-Changing Diagnosis, and the co-hosts of The Waiting Room Revolution podcast.

Tommy Whitelaw

National Lead Person Centred Voices,
Alliance Scotland



Title of talk:

'You Make a Difference (intelligent kindness)'



Bio:

Tommy leads on the Person-Centred Voices project, encouraging culture change on person centred practices across health and social care.

Tommy engages with health and social care professionals and students to encourage them to reflect on the difference they make through the care they provide, asking 'what works well?' but also 'what can we do differently in the future?'.

Tommy travels throughout the country delivering talks and workshops to care homes, hospitals, universities, and colleges, sharing best practice on the delivery of compassionate and person-centred care. Based on his own experience as a former carer and the key messages of the 'Intelligent Kindness' and the 'What Matters to You?' movement, Tommy's engagement work seeks to embed culture change on kind and compassionate workplaces and services.

Special interests: Culture change on person centred care; Supporting people and their carers; The 'What Matters to You?' movement; Improvement of health and social care services.

Zoe Harris

CEO, My Care Matters



Title of talk:

**'What do you want?
Planning for the future:
why it matters and
where to start'**



Bio:

Zoe is the founder and CEO of My Care Matters, a not-for-profit social enterprise with a mission to improve people's experience of care in any care setting: hospital, care home or in their own home. My Care Matters has produced multi-award-winning products and services since 2011, initially inspired by Zoe's late husband's experience of living with, and dying from, dementia.

Zoe led on the research, development and creation of the My Future Care Handbook, a jargon-free and easy-to-use interactive guide to everything we need to think about and plan for when contemplating our future.

My Care Matters provides training and ongoing support to staff and volunteers of organisations, working with people who would benefit from making plans for later life, to use the Handbook as a source of information and structure for the conversation.

See myfuturecare for further information.

Usha Grieve

Director of Partnerships & Services,
Compassion in Dying



Title of talk:

'What do you not want to happen?'
Advance Decisions and how they help



Bio:

Usha Grieve specialises in the legal rights that can enable people to plan ahead for their treatment and care, and the support needed to ensure each individual has the death that is right for them.

She is Director of Partnerships & Services at Compassion in Dying, a charity that supports people to make decisions about and plan for the end of life and is particularly interested in the interaction between communities and healthcare practice when people are approaching the end of their lives.

She has written on advance decision-making, the barriers and motivators to planning for the end of life and digital care planning.

Wayne Martin

Professor of Philosophy,
The Autonomy Project,
University of Essex



Title of talk:

**'Ethical and Policy Dilemmas in (DNA) CPR
Decisions: Results from the Autonomy Project Audit'**



Bio:

Wayne Martin is Professor of Philosophy at the University of Essex, where he directs the Essex Autonomy Project, a multi-disciplinary research and public policy initiative focusing on decision-making, human rights, and the ideal of self-determination in care settings.

Further information about the work of the Autonomy Project can be found on the project website: <http://autonomy.essex.ac.uk>

Clare Fuller

Advance Care Planning Advocate,
Educator & Coach and LPA Consultant
- Speak For Me



Title of talk:

'Who would speak for you?'



Bio:

Clare is a Registered Nurse with 30 years' experience in End-of-Life Care (EoLC). She has worked in hospices, the community, and acute sectors as a Clinical Nurse Specialist, and at a national level as a Consultant Nurse for the Gold Standards Framework. Clare is a CQC Specialist Advisor for EoLC and a Lasting Power of Attorney Consultant.

Clare is the owner and director of Speak for Me which helps organisations to improve EoLC and provides professional and public education about Palliative and End of Life Care and Advance Care Planning.

Clare campaigns for proactive Advance Care Planning and hosts the podcast Conversations about Advance Care Planning .

James Norris

Founder of My Wishes & The Digital Legacy Association



Title of talk:

'Getting your digital life in order'



Bio:

James is the founder of MyWishes and the Digital Legacy Association, he also holds the post as the Digital Research Fellow at Michael Sobell Hospice (London). Over the last 13 years James has developed and explored the use of technology to help improve end of life communication, planning and care. In 2015 he launched the Digital Legacy Association CIC at Hospice UK's annual conference to support professionals and the general public in areas relating to digital assets planning and digital legacy. MyWishes takes both a public health approach and a digital first approach to advance care planning. It empowers society to document their future health and wider wishes. Its content, structure and design has been developed to help introduce care planning to society at an early stage and normalise this behaviour by incorporating it alongside other better-known tasks (will writing, funeral planning, bucket lists etc).

James continues to consult various governmental and non-governmental organisations across the globe in areas relating to death and the internet. He provides thought leadership in areas relating to death, bereavement, technology and the internet on TV, online, print and in scientific journals.

Suzie Taylor



Title of talk:

'Panel - Journey through Advance Care Planning'



Bio:

My name is Suzie and I live in Norwich with my husband and son. I work as a PA to the CEO of a charity and was living a pretty normal life when I was diagnosed with cancer of the bile duct and liver in the summer of 2022.

The outlook wasn't good and although I could go on for ages the main point is that I'm still here. In my darkest days I started to wonder how things would be for me when I got too ill to make my own decisions about my health and finances. I'm a pretty exacting person so it was important for me to have my wishes known to all.

This is when I started to research advance care planning.

Dr Louisa Grant

Palliative Care Consultant,
Norfolk and Norwich University Hospital



Title of talk:

'Panel - Journey through Advance care Planning'



Bio:

Lou Grant is a Consultant in Palliative Medicine at Norfolk and Norwich University Hospital. Her areas of specialist interest are Hepatobiliary disease, and palliative care for young people and inclusion health groups, and the development of non traditional models of care that better support the particular and significant needs of these groups.

She has Masters in Gastroenterology and completed a fellowship in Toronto where the focus of the work was developing a palliative and supportive care service for patients with end stage liver disease including those awaiting transplantation.

Thank you from Palliative Care NNUH to:

N&N Hospitals Charity for SPONSORSHIP

To all Speakers for their time and dedication

**To all the organisations, public compassionate communities groups who
have Live Streamed to raise awareness**

To all the services and charities for their awareness stands

**To all volunteers and staff who have helped to plan, organise and host the
conference**

St John Innes Centre for Hosting

Live stream

Graphics (Medical Illustration) and Communications team NNUH

To all the services and charities for their awareness stands

To all supporters that have contributed to the conference

**And to all attendees for your dedication and passion towards raising
awareness of Advance Care Planning**



Norfolk & Norwich
Hospitals Charity



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