



DIGESTIVE CANCERS
EUROPE

Oesophageal Cancer

A Patient Perspective

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A tale of twins...



- Similar primary cancers
- Would I have the same fate as my twin brother?
 - Has it spread?
- How long have I got?
 - Who do I talk to?
 - Will it come back?
- What will happen to me?

Oesophageal Cancer: Why me?

Relatively uncommon especially in women, and even more so in Asians compared with white populations

Risk factors? – lifestyle? Genetics?

Low survival rates (5 year 5-30% in those amenable to treatment; 12% for 10 years)

National Cancer Intelligence Network and Cancer Research UK, 2009 [Cancer Incidence and Survival by Major Ethnic Group, England, 2002-2006](#)

Lorelei A. Mucci et al on behalf of the Nordic Twin Study of Cancer (NorTwinCan) collaboration. Familial risk and heritability of cancer among twins in Nordic countries. *JAMA*, January 5, 2016 DOI: [10.1001/jama.2015.17703](#)

What impact did OC and gastric cancer have on us?



Dealing with cancer diagnosis

Communication with patients and families (diverse cultural backgrounds)

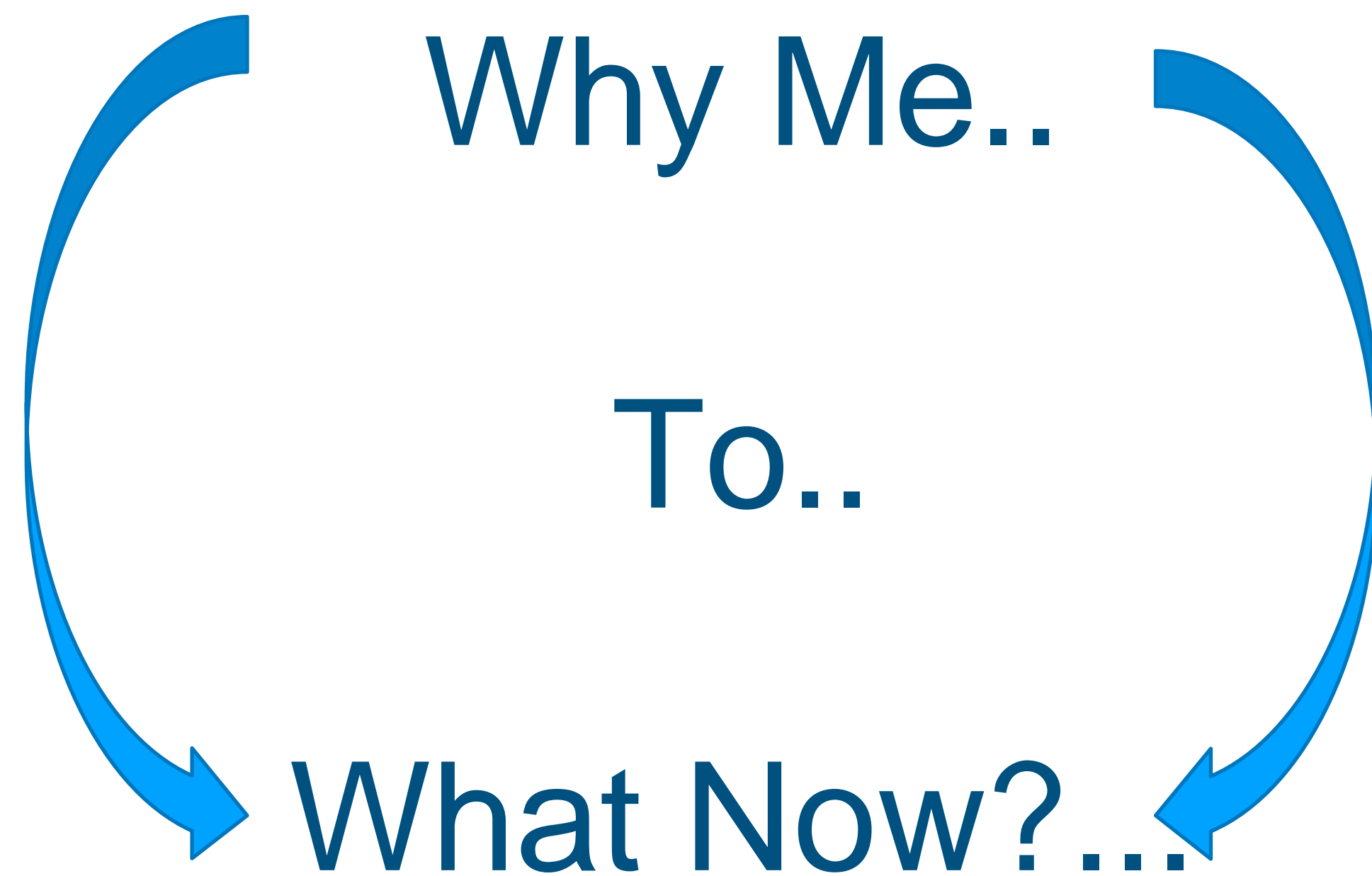
Assuming the worst

Information and support

Living with uncertainty

Source: *British Medical Journal* 16 March 2019; D.Trivedi Assuming the worst.
<https://www.bmj.com/content/364/bmj.l788>

“Experience is not what happens to you..it’s what you do with what happens to you..” Alduous Huxley



- Shock, fear, anxiety and cascading uncertainty
- Emotions under siege
- **Treating patient, not just the disease**
- The importance of “being well...”
- Building trust



Treatment and beyond; What did I need the most?

- Quality of life
- Emotional health
- Mental wellbeing
- Physical challenges
- Pain management
- Nutrition and dietary needs
- Carer needs?
- Coping mechanisms?

Self-empowerment – making our lives better

- *Access to appropriate support **from the outset- recommendation***
- *Diet and fitness*
- *Positive mindset*
- *Practising mindfulness – focus on what I can control, letting go of what I cannot*
- *Holistic health - quality of life, coping, resilience*
- *Faith, hope, & courage to face the challenges*
- *Local support group for patients and carers- learning to talk about cancer, inviting health professionals, signposting: Asian Women's Cancer Group, UK*
- *Healing art, music, walking – therapeutic activities*



Digestive Cancers Europe

Dietary Advice Booklet for Patients with Oesophageal or Gastric Cancer

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What do patients and carers need?

- The need to understand what is happening at each stage of the journey
- Appropriate, ongoing and timely support to alleviate anxiety, psychological impact
- Pre-and post operative phases – needs change (now, prehabilitation support)
- Holistic Needs Assessment Tool? (<https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holistic-needs-assessment>)
- Personalised care and support plan for family - cancer navigators?
<https://www.imperial.nhs.uk/our-services/cancer-services/macmillan-cancer-partnership/macmillan-cancer-navigators>
- Research studies and trials to identify patient relevant outcome measures and develop appropriate interventions
- Early detection?

Helping to improve patient well-being

- *Senior Researcher – interest in health inequalities, cancer research, public health*
- *Member of the Cancer Outcomes Project (Luton), Research input, NHS England & NHS Improvement, East of England, UK*
- *Chairperson, Mid-Bedfordshire Cancer Support Group, UK (Macmillan, UK)*
- *Member of the Asian Women's Cancer Group, UK*
- *Member of the Rapid Diagnostic Cancer Services Steering Group, Bedford, Luton & Milton Keynes (BLMK), UK*
- *Member of Patient forum of BLMK Cancer Alliance Integrated Care Services Programme, UK*
- *Member of the National Cancer Research Institute, Living With and Beyond Cancer Research Group*
- *Patient representative in Clinical Trials*

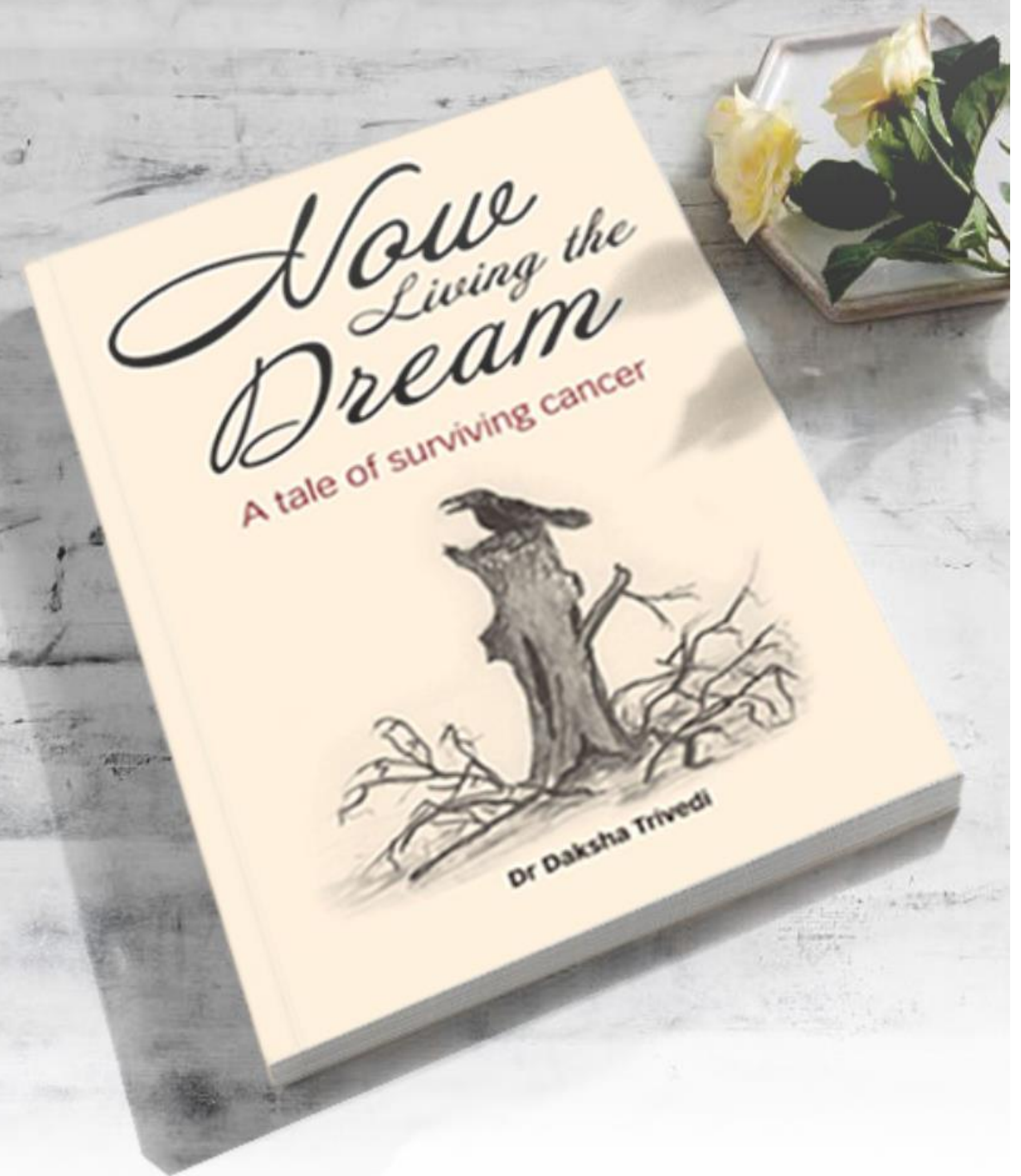


Yes, to Life..!

How Living the Dream

A tale of surviving cancer

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**Thank you...
Questions?**