

Survivorship in Cancer

Colorectal cancer

Claire Taylor

Lecturer in Gastrointestinal Nursing,

Burdett Institute

Kings College, London

*Consequences of Cancer Treatment Collaborative (CCaT)
National Cancer Survivorship Initiative (NCSI)*

Cancer today is a curable disease for many
and a chronic disease for most

Cancer patients can look forward to a vastly
improved disease-free and overall survival

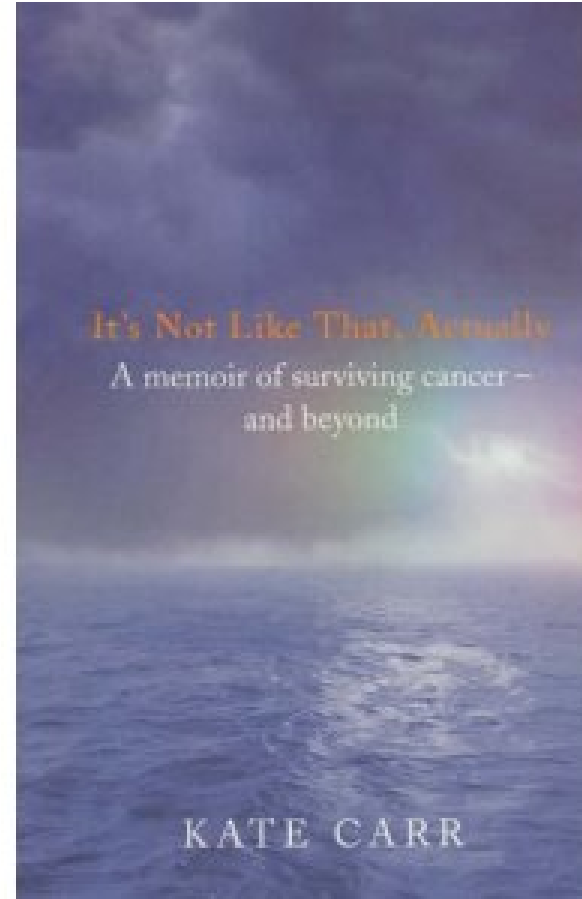
Survivorship

“A cancer survivor is someone who is living with cancer or who has had cancer” Macmillan Definition

- For some authors, the process begins at diagnosis...
- ... others suggest a person must live for at least 5 years before being regarded as a survivor...

How do you define cancer survivorship ?

' Its not like that
Actually'



Survivorship as a process

Mullan's (1985) seminal work '[Seasons of Survival](#)' describes survivorship as beginning at diagnosis and continuing through 3 seasons;

acute

extended

permanent

The significance of survivorship

Surviving cancer is now an established reality for millions of people worldwide

There are currently 2 million such people in the UK

By 2030 there will be 3 million cancer survivors in the UK

CRC patients make up 11% of all cancer survivors (Aziz, 2002)

Diversity of sequelae

Positive and negative outcomes following a cancer diagnosis....

Positives are generally linked to **feelings of self-improvement**, personal growth, appreciation of life, and an improvement in relationships

Negatives are mainly associated with **medical and physical issues** such as depression, fatigue, pain, dyspnoea cognitive impairment, sterility and loss of sexual function

Life Changing Experience

The opportunity to redefine oneself does not occur often in life, but a cancer diagnosis may be one of those occasions....

- Assessment of what is important in life, search for meaning and sense of mortality
- Transformative potential (De Marco et al, 2004)
- Differences in male and female response (Mellon et al, 2006)

Macmillan Study of the Health and Well-being of Cancer Survivors Macmillan Cancer Support, 2008

- 78% have experienced physical health problems in the last 12 months.
- 40% with emotional problems have not sought help.
- 40% say they are unaware of long-term side effects.

(Sample 442 individuals with cancer across the UK)

The year after treatment



1850 patients (breast, prostate, gynaecology, CRC, NHL) from 66 centres

79% completed questionnaires at EOT & 6 months later



25% unmet needs 6 months after treatment

Armes et al JCO 2009

Uncertainty inextricably linked to surviving cancer

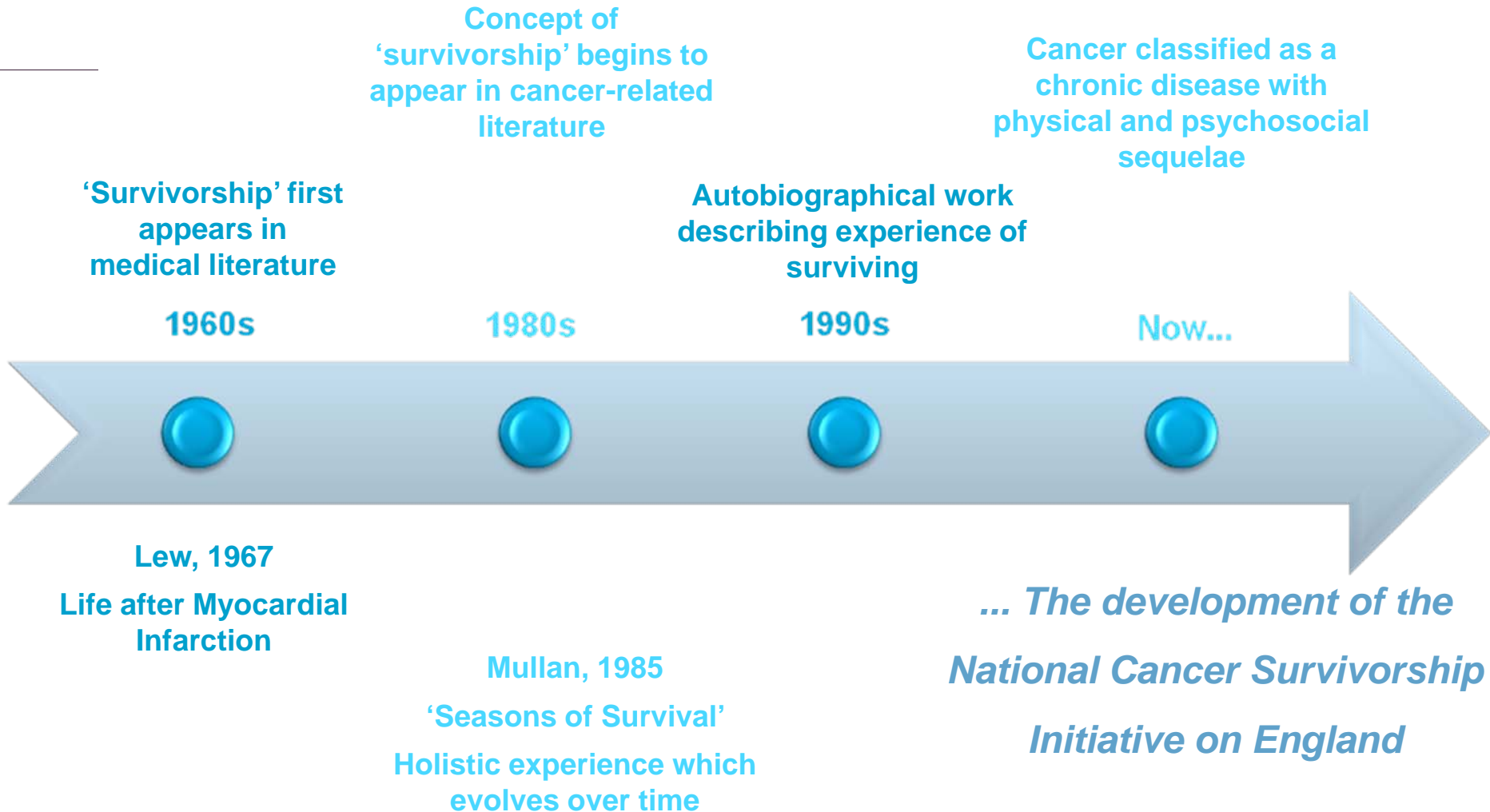
- Feelings of powerlessness (Armstrong 2001 and Carr 2004)
- Unsure of what to do with self
- Fear of recurrence (Denlinger and Barsevick, 2009)
- Dichotomy of feelings around check-ups and anniversaries (Vachon 2001)

3 elements common to cancer survivors:

- 1) Adhesiveness of the label 'cancer patient'
- 2) Awareness of the body's fallibility
- 3) Knowledge that the individual has lived through an intense experience that is unique to them

(Little et al 2000)

A brief history of time...



National Cancer Survivorship Initiative NCSI - 7 Work streams

Each workstream focuses on either a stage in the 'survivorship pathway' or connecting theme;

- 1) **Assessment and Care Planning**
- 2) **Managing Active and Advanced Disease**
- 3) **Consequences (Late effects)**
- 4) **Children and Young People**
- 5) **Self-care and Self-management**
- 6) **Work and Finance**
- 7) **Research**

NCSI Test Communities

Assessment and Care Planning

Work is underway within NCSI to improve the after-care these patients receive by testing new models of care

7 new prototype test communities to implement and evaluate whole pathways of care for patients

Guys and St Thomas' Hospitals - Colorectal

National Cancer Survivorship Initiative (NCSI) - Adult Test Communities

- Models of Care
- Assessment Care Planning



Survivorship needs of individuals after colorectal cancer

Physical - change in strength and endurance, urinary, sexual and bowel function, fatigue, late toxicities from treatment

Psychological - living with compromise, fears and uncertainty, change in body image

Social - change in interpersonal relationships

Financial - return to work, cost of cancer

Quality of life in CRC survivors?

‘those who achieve long-term remission may experience relatively high QOL although physical symptoms such as depression remain a problem’ (Ramsey et al, 2002)

- 40% of people 15yrs post-diagnosis receive cancer-related care

6 x less able to work > 65yrs

- Spectrum of treatment side-effects from low grade to catastrophic but not routinely recognised, documented or managed

Who is most at risk?

Those having low rectal anastomosis =/- formation of temporary stoma -post-op /reversal bowel symptoms

Permanent ostomists - psychosocial effects

Those requiring multimodal cancer treatment

Individuals from ethnic minority groups, low literacy groups

Individuals who are single, socially isolated or lacking social support

Older cancer survivors, with co-morbidities or mobility problems

Survivors with ostomy

- Reported to have more complications early in their survivorship period than non-ostomates (Lui et al, 2010)
- Whilst both male and female ostomists have worse social well-being cf controls, only female cases had significantly worse overall HRQOL and psychological well-being - particularly if age 75 years) (Krouse et al, 2009)
- More problems with flatus or gas, dietary restrictions, and risk of leakage, spillage and accidents. Higher prevalence of depression but not anxiety. Restriction in social activities and less likely to return to work than non-ostomates. (Williams Johnston, 1983)

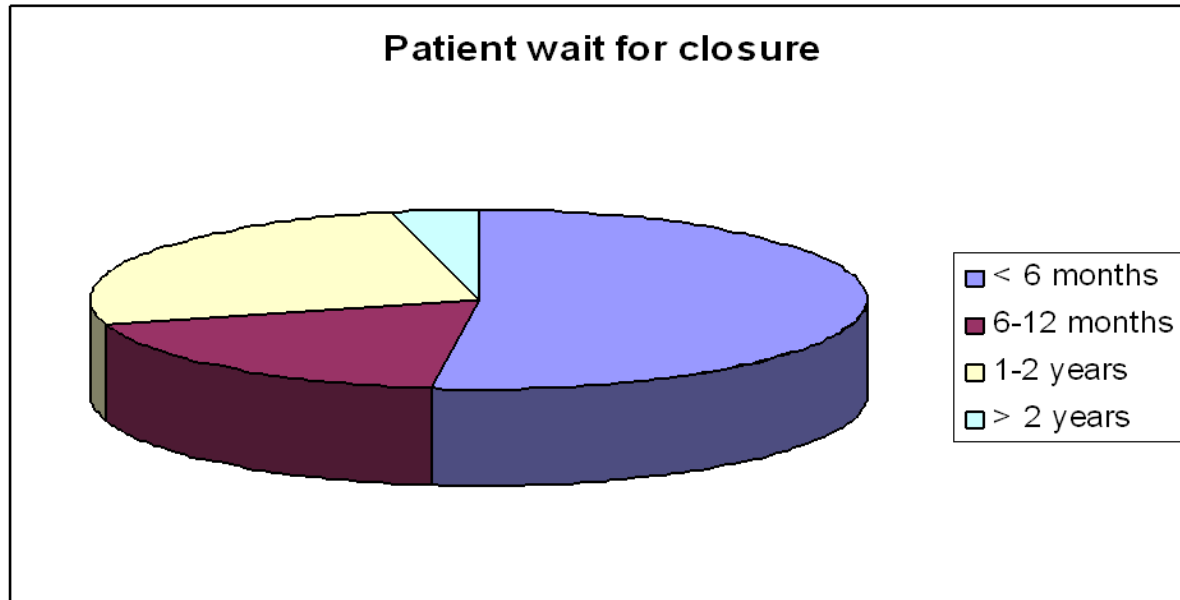
Stoma Reversal

- 30-80% AR have a temp. ileostomy (NBOCAP2009)
- Post stoma closure dysfunction
- Significant majority of stomas never reversed e.g. only 67% reversed (n=141) (Kairaluoma et al, '02) but variation reported with closure rates as high as 96% (Hallbrook et al '02)
- Certain risks associated with the operation incl. need for repeat laparotomy, adhesional small bowel obstruction and possibility of prolonged hospitalisation (Chow et al, '09)
- Some patients derive no benefit from being defunctioned

Reversal of ileostomy patient survey

- A two-page postal questionnaire developed
- Patient satisfaction and wait for reversal
- All pts who had had a stoma reversal in 2009 and alive on 20th March 2010 incl. N= 61 patients.
- Response rate = 48% (30)

Findings and outcomes



Perceived reasons for delay:

- Need for further treatment = 6
- They did not feel fit enough= 4
- There was a lack of operating time=1

The patient experience

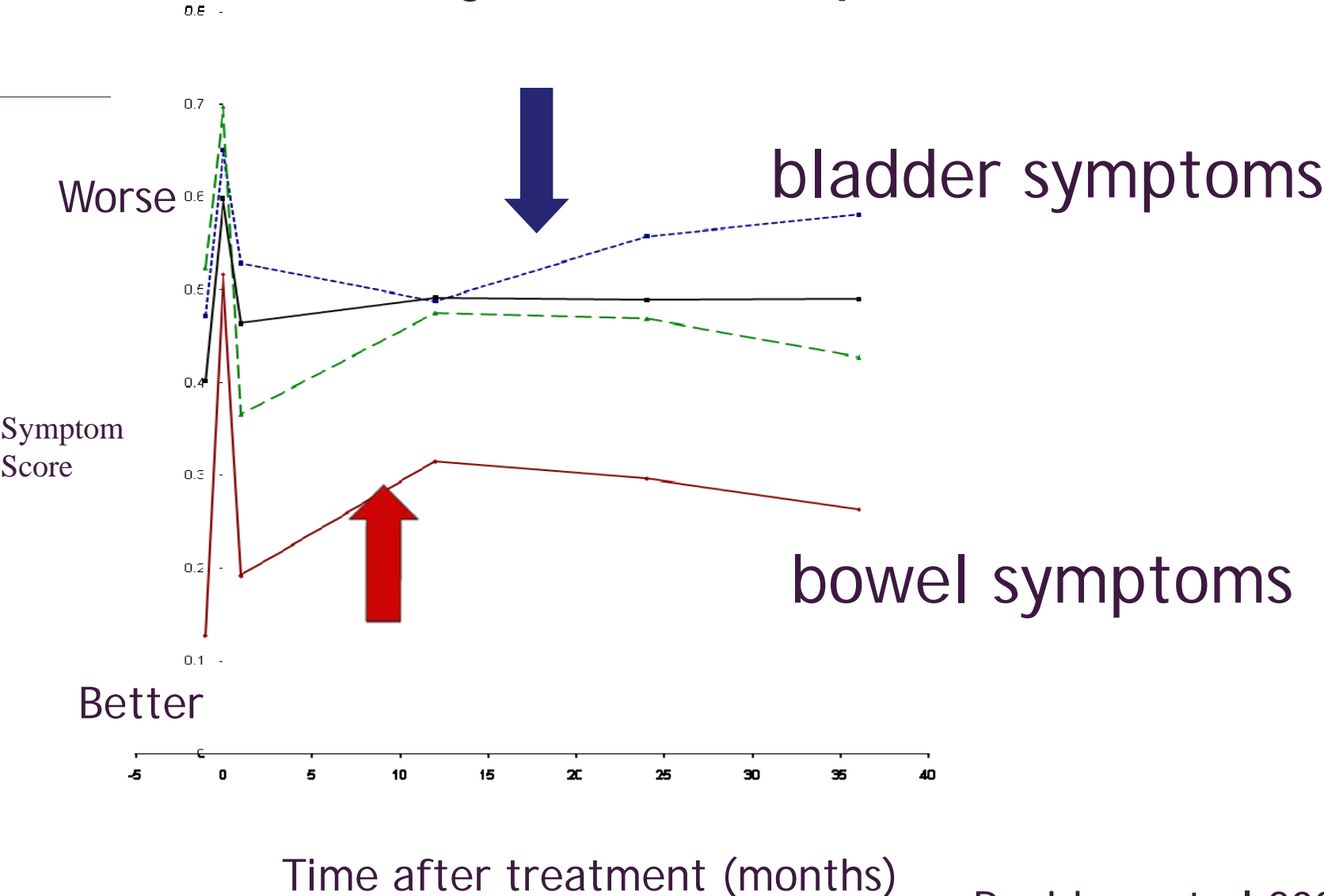
‘ If someone had just said that I’d have some bowel problems after the closure but that whilst they couldn’t say exactly how I’d be..but that usually these symptoms do improve over time, then that would have been fine’

Man 62 yrs- LAR 2006, 2 years of bowel symptoms before he was referred by CNS

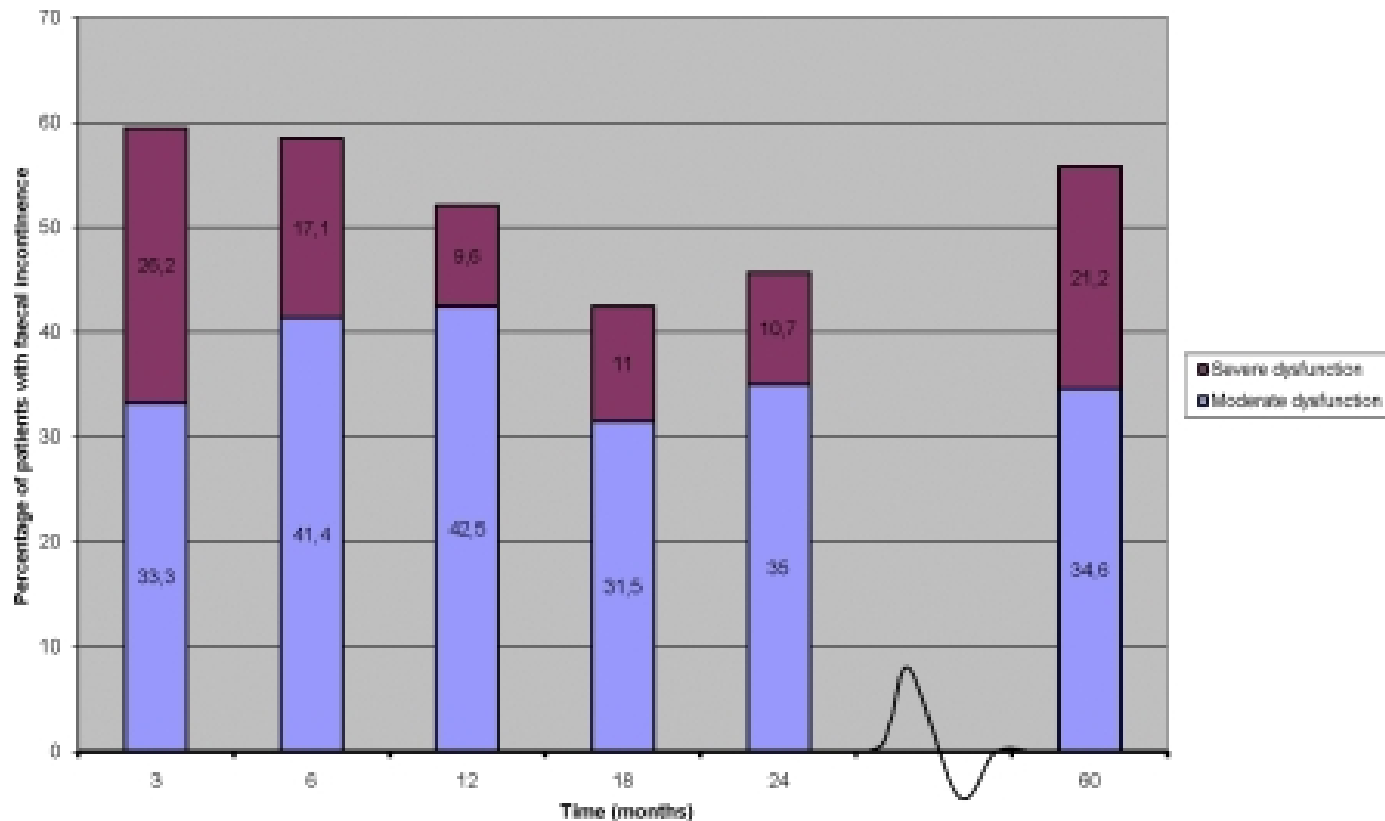
Effect of surgery on bowel function

- Post AR - typical frequency x4/day (Shibata et al, 2002)
- Clustering of bowel motions
- Median delay until defecation 14 minutes
- 1/3rd incontinent of gas (Matzel et al, 1997)
- Faecal incontinence - 50% at 3/12 (Siassi et al, 2008)
- Improvement over time (Tsunoda et al, 2007; Engel et al, 2003)
- Significant % still have problems @1 yr

Months /years after pelvic RT



Incidence of Moderate and Severe Faecal Incontinence Reported by Patients Treated with Pre-Operative RT



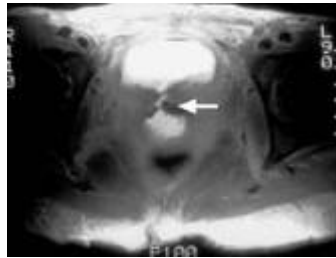
Kapiteijn et al. 2001 Preop RT combined with total mesorectal excision for resectable rectal cancer. *N Engl J Med.*;345:638–646.

Severe Adverse events :

5 -10% after 10 years; >10% after 20 years



Stricture



Fistula/
Perforation



Transfusion
dependent
bleeding



Secondary
cancer

Eifel 1995, Nostrant 1995, Denton 2000, Ooi 2000, Andreyev 2005

If we don't treat such symptoms..

- Reduced emotional health - leading to anxiety & depression
- Effect on relationships - breakdown and social isolation
- Reduction in productivity

with direct and indirect costs to the healthcare system

Deutekom et al (2005) Impact of faecal incontinence on health domains. *Colorectal Dis*; 7: 263–9.

Current management of side-effects

- May or may not be addressed during FU
- Haggstrom et al 2009 Symptoms and side-effects infrequently addressed during CRC follow-up
- Wait to see if it gets better
- Very few systematically monitor

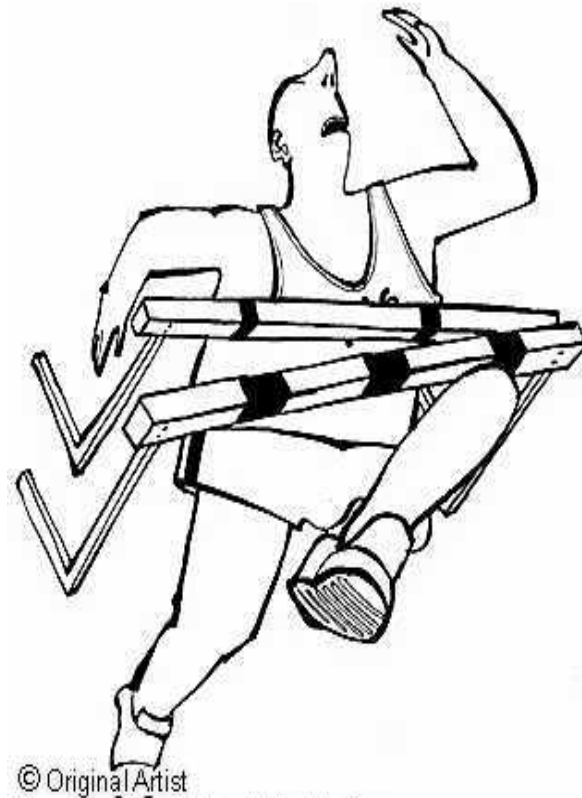
Assessing bowel function: questions

- What is the main problem with your bowels?
- How often do you open your bowels?
- What is your stool like and does it vary?
- Do you ever fail to reach the toilet in time?
- Do you ever have any leakage from your bowel of which you are unaware?
- Can you control wind?
- Are you able to tell the difference between wind and the need to empty your bowels?
- Do you have any difficulty opening your bowels?
- Does it ever feel as if you have not completely emptied your bowels

Psychological and social issues

- 25% of all Ca pts will meet criteria for an adjustment disorder
- 1/3 of CRC survivors experience an episode of depression (Tsunoda et al, 2005).
- Modest improvements in emotional functioning occurring over time are noted (Arndt et al, 2006)
- Need to protect others - prevent emotional disclosure

Helping individuals recover following treatment - what makes the difference...



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Time taken to recover following colorectal cancer treatment?

- Acute survival - symptoms generally settle by 6/52
 - pain, bowel urgency/frequency, difficulty sleeping/ eating/mobilising, wound healing
- The majority of patients feel able to resume nearly all activities by 3/12 e.g. return to work
- Extended survival - by one year most have appraised their situation and been able to put the trauma behind them, with continuing (intermittent) fears of cancer recurrence
- A minority will have chronic effects.

What do patients want...

- help to cope with their cancer and its treatment
- to maximize the benefits of their treatment
- to live as well as possible.

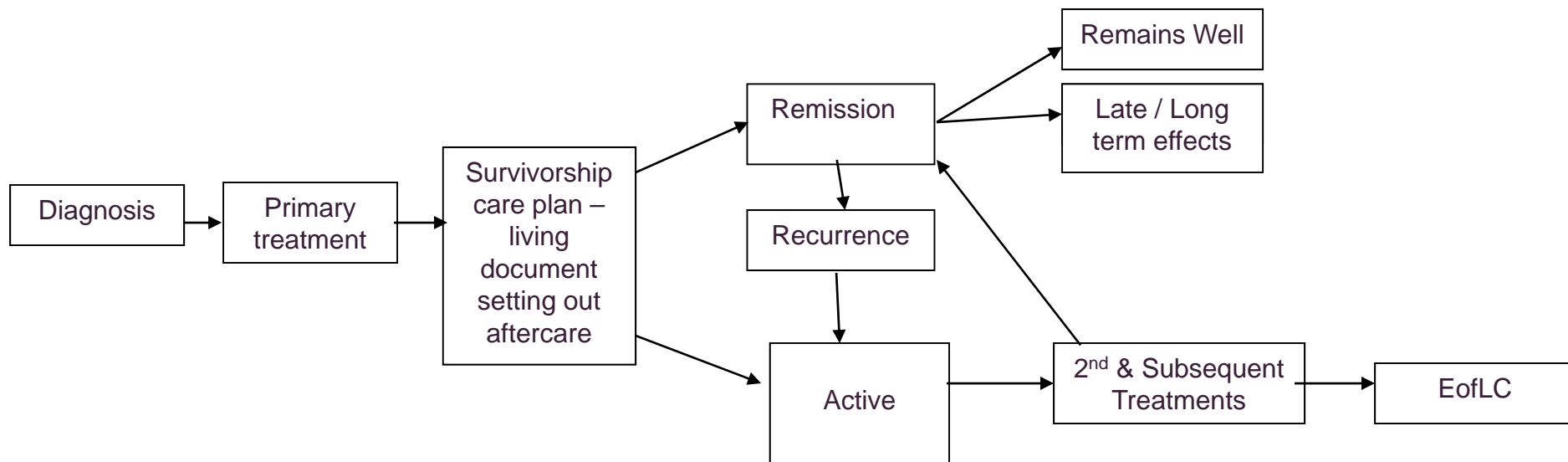
Work in progress...

The current system isn't working for patients

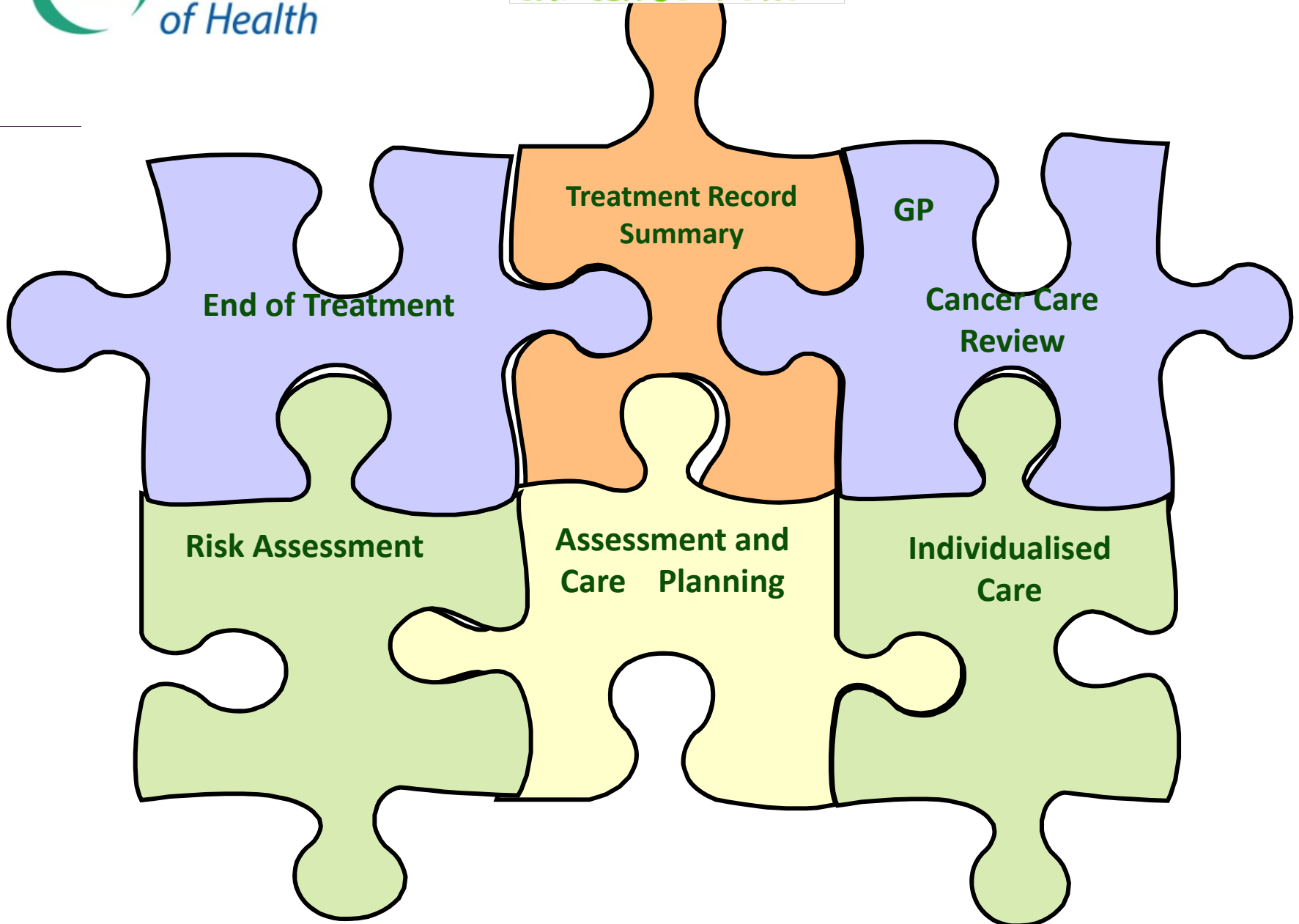
- We need to move from single model of follow up to a program of after-care so that people get the right treatment and support
- Avoidable consequences avoided
- Unavoidable consequences recognised & managed to minimise disability

National Cancer Survivorship Initiative

Survivorship Care and Support Pathway



Crosscutting themes of work/education, finance, self management, research, information, commissioning



Nursing care

- Recognition of our major role in promoting QOL in cancer survivors
- Monitoring their health holistic
- Recording Patient Reported Outcome Measures PROMS
- Health promotion - diet, wt reduction, increase exercise
- Self-management

Survivorship care plans

- Everyone who finishes treatment should be offered a post-treatment holistic needs assessment.
- As part of that plan, information provided about possible consequences of cancer and its treatment.
- Care plan includes surveillance protocol
- Shared with key MDT members incl. GPs
- Use strongly supported by CRC patient group.
Baravelli - J Ca Surv 2002

After-care programmes

Psycho-educational

Transitions, Moving Forward

Lifestyle

Exercise programmes

Health and well-being clinics

One day educational events



Improving survivorship

"The real voyage of discovery consists not in seeking new landscapes, but in having new eyes"

Marcel Proust



Conclusions

We need to consider how we are going to provide for the growing number of cancer survivors

It is time to review our after-care provision

A holistic needs assessment at the end of treatment

Increasing evidence for secondary prevention



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**Enabling
individuals to get
the care and
support they need
to lead as healthy
and active a life as
possible, for as
long as possible**

