

Living With and After Cancer.

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UKONS President 2012 - 2014

BAUN Renal Cancer Study Day - February 2014



Why I do what I do... (why do you do what you do?)

“The goal of cancer nursing should be to assist the person to be a fully functioning person first and a cancer patient second”

Poletti 1983



Setting the scene for this whistle-stop tour!

- There are currently around two million people living with or beyond cancer in the UK

Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547.

- The number of people living with cancer in the UK is increasing by 3.2% every year – if this rate continues this could see four million people living with cancer by 2030

Internal analysis by Macmillan Cancer Support. Taken from and based on Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547



Survivorship... A Concept Analysis

“Cancer survivorship is a process beginning at 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



Survivorship...5 Attributes

- **A process beginning at diagnosis**
- **Uncertainty**
- **Life changing experience**
- **Duality of positive and negative aspects**
- **Individual experience with universality**

Doyle 2008



Survivorship...The consequences

Physical
Psychological
Social
Spiritual



Function
Relationships
Body image
Intimacy
Fertility
Sexuality
Social
Occupational
Routines
Spirituality
Quality of Life

Dow et al 1999



Survivorship...Lost in Transition

Cancer patient

Cancer survivor

IOM 2006



Semantics

- **Don't call me a survivor**
- **I'm glad to be alive...call me what you like**



Why is the survivorship agenda so important ? Why does it matter?

“The party, such as it was,
was over”

Carr 2004



What should we be doing?

- ✓ Knowledge & understanding
- ✓ The recovery package
- ✓ Professional attitude
- ✓ And remember...change can be good



How many people survive kidney cancer?

- In Scotland, the majority of those with kidney cancer survive between 1 and 5 years.
- Around half of people diagnosed with kidney cancer in England survive their disease for at least five years after diagnosis.
- Ten-year survival rates for people diagnosed with kidney cancer in England and Wales have almost doubled in the last 40 years.
- In England, around 40% of people diagnosed with kidney cancer are now likely to survive their disease for at least ten years.

(Cancer Research UK 2013 & NHS Scotland 2010)



What happens next?

–30% of people reported 5 unmet needs a year after diagnosis

Armes et al 2009



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



Consequences of Treatment

Hundreds of people

Example: Severe, complex late effects from obsolete breast radiotherapy technique in 1980s

Tens of thousands

Example: Of the tens of thousands alive after pelvic radiotherapy, many have long term impact on bowel, urinary & sexual function. Estimate 50% of the 17,000 per year receiving pelvic radiotherapy will have bowel problems and need specialist help

Hundreds of thousands

Example: The hundreds of thousands alive >5 years after breast, prostate & colorectal cancer need attention for increased risk of CVD & osteoporosis



NCSI 2012: Five key elements

1. Support through primary treatment from point of diagnosis
2. Promoting recovery
3. Sustaining recovery
4. Reducing the burden of consequences of treatment
5. Supporting patients with active and advanced disease – interfacing with end of life care services



The Goal...

“...being to support cancer survivors to live as healthy and active a life as possible for as long as possible.”

Richards et al 2011



The Recovery Package



The Recovery Package

- **Holistic Needs Assessments and Care Planning** – at key points of the care pathway
- **Treatment Summary** – completed at end of acute treatment phase and sent to GP.
- **Cancer Care Review** – completed by GP or practice nurse to discuss persons needs, and
- **Patients education and support event**, such as Health and Wellbeing Clinics to prepare for:-
- **Transition to supported self management**, which will include advice on healthy lifestyle and physical activity.



What is Holistic Needs Assessment (HNA)?

“A holistic health and social care assessment undertaken in order to identify supportive and palliative care needs of an individual and to trigger any specialist assessment that may be required”

NCAT 2007



Holistic Needs Assessment (contd.)

- ✓ The process of assessment should be one of partnership between patient and professional.
- ✓ Self-assessment is a useful way to identify issues of particular concern to the patient, for subsequent discussion with the assessor.
- ✓ Assessment should take no more than 30 minutes on average.

NCAT 2007



What should be included in an assessment?

- ✓ Background information and assessment preferences
- ✓ Physical needs
- ✓ Social and occupational needs
- ✓ Psychological well-being
- ✓ Spiritual needs

NCAT 2007

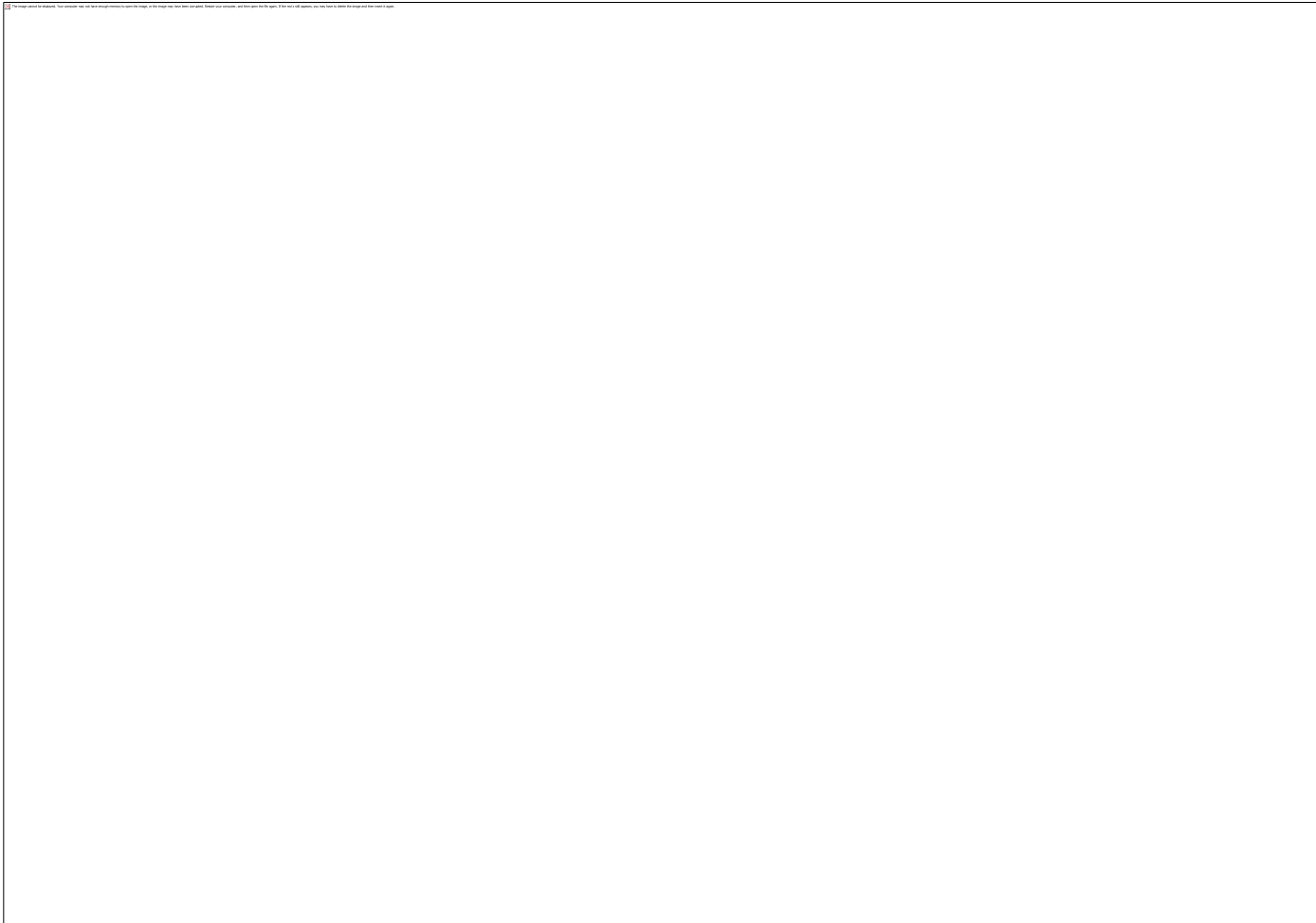


Key points of assessment

- ✓ Around the time of diagnosis
- ✓ Commencement of treatment
- ✓ Completion of the primary treatment plan
- ✓ The point of recognition of incurability
- ✓ The beginning of end of life
- ✓ The point at which dying is diagnosed
- ✓ At any other time that the patient may request
- ✓ At any other time that a professional carer may judge necessary
- ✓ Each new episode of disease recurrence



The New Pan-London Tool



Care Plan

A large, empty rectangular box with a thin black border, intended for writing the care plan.



The Professional Challenge

- Spirit is willing but the flesh is weak
- Time is the enemy
- Talk of other concerns
- What happens when there isn't anything you can do?
- If it isn't documented it didn't happen
- The Official Secrets Act



Assessment the old fashioned way:

- How do you know what someone is thinking or is concerned about?
- Do you second guess based on experience?
- Do you always get it right?
- Would you know if you were wrong?
- Are you surprised when you are wrong?
- What happens then?



Self Efficacy Theory

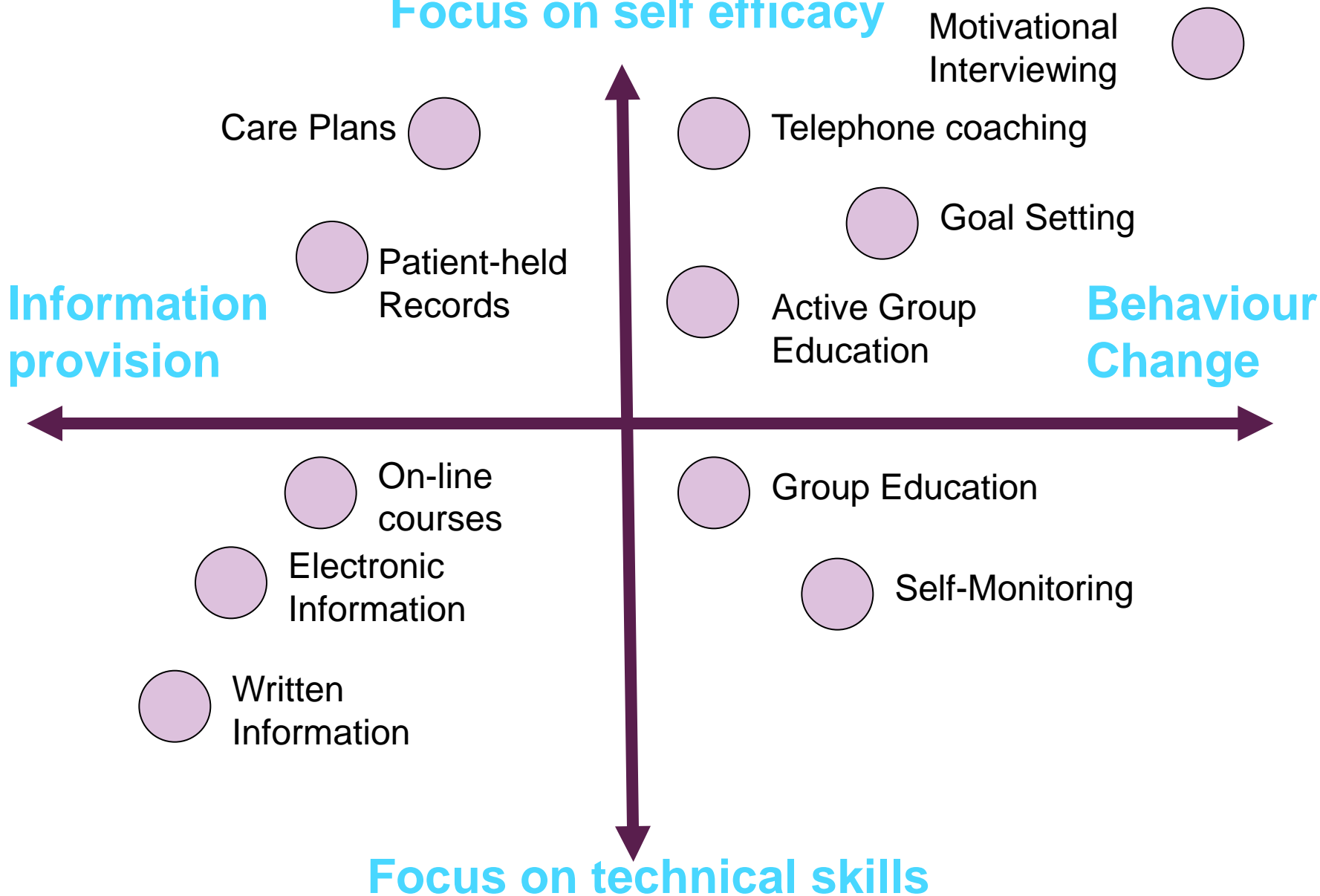
A person's sense of self-efficacy (mastery) is influenced by:-

- ✓ Achievements (positive performance feedback)
- ✓ Physiological states (low stress)
- ✓ Vicarious experience (see others achieving)
- ✓ Verbal persuasion (Strengthening expectation)
(in order of significance)

Bandura 1977



Focus on self efficacy



Utilising the Teachable Moment

Opportunities exist to promote lifestyle changes that may improve the length and quality of life.

Demark-Wahnefried et al 2005



Because it ain't what you do...

**It's the way that you do it
And that's what gets results**

Bananarama & The Fun Boy Three 1982



Communication is the key

- ✓ Solution focused care
- ✓ Motivational interviewing



10 Top Tips for patients following cancer treatment created by CCaT

- ✓ Discuss your needs and develop a care plan
- ✓ Ask about a treatment summary
- ✓ Find your main contact
- ✓ Be aware of any post-treatment symptoms
- ✓ Get support with day to day concerns
- ✓ Talk about how you feel
- ✓ Try to lead a healthier life style
- ✓ Know what to look out for
- ✓ Be aware of your own health
- ✓ Share your experiences

(Booklet MAC13615)



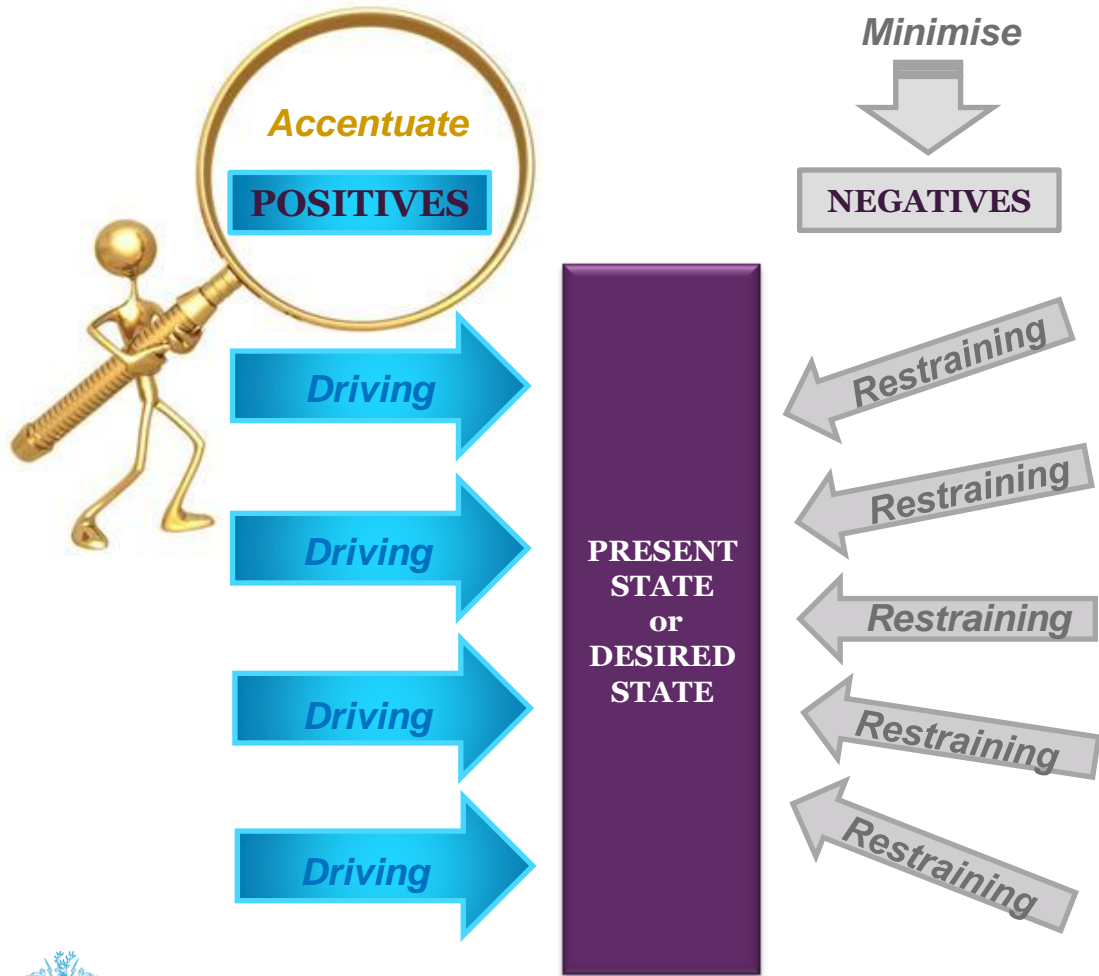
After Cancer Treatment: A guide for Professionals created by CCaT

- ✓ How you can discuss needs and develop a care plan
- ✓ How to complete a treatment summary
- ✓ How to provide main contact
- ✓ How to raise awareness of any post-treatment symptoms
- ✓ How to promote professional and peer support for day to day concerns
- ✓ How to support people to talk about their feelings
- ✓ How to promote a healthier life style
- ✓ How to prepare people to know what to look out for
- ✓ How to support people to be aware of their own health
- ✓ How to encourage people to share their experiences

(Booklet MAC14302)



Harnessing the Forces for Change...



**Essentially, focussing
our energies on
people who were
motivators and
enablers!**



Applicable to Everyone

“Self efficacy is a belief in one’s ability to achieve something”

Bandura 1977



#NatalieDoyleSaidSheDoesn't
KnowButWillFindOut



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