

Psychological Wellbeing & Mental Health in Prostate Cancer

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**PROSTATE
CANCER UK**

Learning Objectives

- Why do Psychological Issues matter?
- Psychological Challenges along the Prostate Cancer journey
- The Breadth of Impact: Going beyond Depression & Anxiety
- Assessing Psychological Need in Prostate Cancer
- Intervention & Onward Referral

Why does it matter?

It is common

- ~50% patients experience levels of anxiety/depression severe enough to adversely affect quality of life
- 1/3 patient continue to report significant levels of distress after treatment (Carlson et al. 2004)
- Carers
 - 67% experience anxiety & 42% experience depression
 - More than $\frac{3}{4}$ get no support

Higher levels of distress

- Lung, Pancreatic, Hodgkin's lymphoma, Brain, Head & Neck, Leukaemia
- Women, those with young children, co-morbidities, lower SES

Why does it matter?

It matters to patients

Electronic Holistic Needs Assessment Data (2017)

Ranking	Concern	Number of e-HNAs	% of patients who had E-HNA with concern
1	Worry, fear or anxiety	3724	38.0%
2	Tired, exhausted or fatigued	2105	21.5%
3	Pain or discomfort	1964	20.1%
4	Eating, appetite or taste	1414	14.4%
5	Sleep problems	1403	14.3%
6	Moving around (walking)	1239	12.7%
7	Work or education	1206	12.3%
8	Sadness or depression	1180	12.0%
9	Money or housing	1172	12.0%
10	Difficulty making plans	1107	11.3%



Why does it matter?

It impacts outcomes & care provision

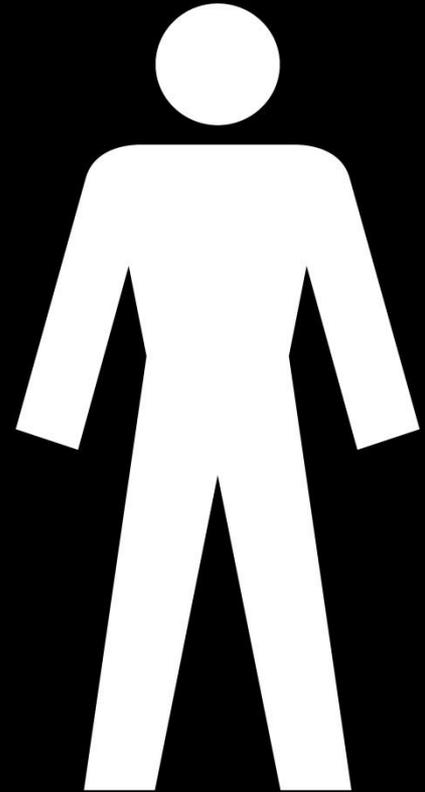
- **Mortality rates**
 - Up to 39% higher in patients with cancer & depression
 - Previous emotional problems --- 2.6x more likely to die within first 19 months post-diagnosis
- **Suicidality**
 - 8% of all people attending cancer outpatients report passive suicidal ideation in preceding two weeks
 - Rate of completed suicide twice that of general age and sex-matched population (even higher for certain tumours)
- **Adherence**
 - 3x more likely to be non-adherent with cancer treatment if suffering from depression
- **GP & A&E attendance**
 - People with mental ill health are three times more likely to present to A&E than the general population

Why does it matter?

It interacts with the rest of life

- Tyranny of positivity
- Responsibility for lifestyle-related cancers
- Unattainable models - “He was so brave, I could never cope”
- Fighting the battle → losing the battle → winners, losers
- Sub/culture → e.g. prostate cancer & virility
- Medical advances → “There must be something they can do”
- Drug funding / pressure groups
- No longer sufficient to survive – less tolerance for s/effects
- Sick role / social expectations of treatment, recovery
- Euthanasia – the good death
- Mental health stigma, “being a man”

2) Psychological Challenges along the Prostate Cancer journey



Diagnosis & Early Management

- Active surveillance/Watchful waiting
 - Impact of diagnosis but no treatment
 - Similar distress/hyperarousal levels to active treatment (Carter et al., 2015; Egger et al. 2018)
 - AS - regular PSA testing, anxiety
 - WW – distress can increase over time e.g. sexual function distress (Bill Axelson et al. 2013)
- Treatment planning
 - Consensus, information giving/retention

Treatment Planning & Psychological Influences

- Surgery
 - commonly value ‘removal’ of cancer (anxiety-driven)
 - opportunity for ‘another/closer look’ at the cancer
- Radiotherapy
 - commonly wish to avoidance of urinary/sexual complications from surgery or anaesthesia
- Active Surveillance
 - can be avoidance of complications as above
 - also commonly result of decisional paralysis or reaction to physician/family ‘pressure’

Treatments & Psychological Impact

- **Surgery (Prostatectomy)**
 - Incontinence
 - Erectile dysfunction
 - Decisional crisis/regret
- **Radiotherapy**
 - Painful urinary frequency
 - Bowel irritation
 - Diarrhoea
 - Incontinence
- **Androgen Deprivation Therapy**
 - Loss of libido
 - Mood swings
 - Weight redistribution
 - Hot flashes
 - Fatigue
 - Physical Changes (e.g. penile)
 - Cognitive Impairment
- **Chemotherapy**
 - Fatigue
 - Hair loss
 - Nausea
 - Pain

End of Treatment / Survivorship

- Particularly **Anxiety & Fear of Recurrence**
 - prevalence of anxiety (18%) significantly higher in cancer survivors than in healthy controls, persisting for up to 10 years (Mitchell et al. 2013)
- Making sense of what has happened – “taking stock”, “grieving”
- Level of support, change in level of attention
- Adjustment to functional/bodily changes & side effects (incontinence and sexual dysfunction) - self-esteem/identity/image, “being a man”, control, confidence
- Lifestyle adjustments e.g. return to work
- Role/identity shifts - “going back?”
- Changes in sense of meaning and priorities
- Relationships, intimacy, communication
- On-going role of cancer - check-ups, reminders, scans
- The “new normal”, expectations re: moving on

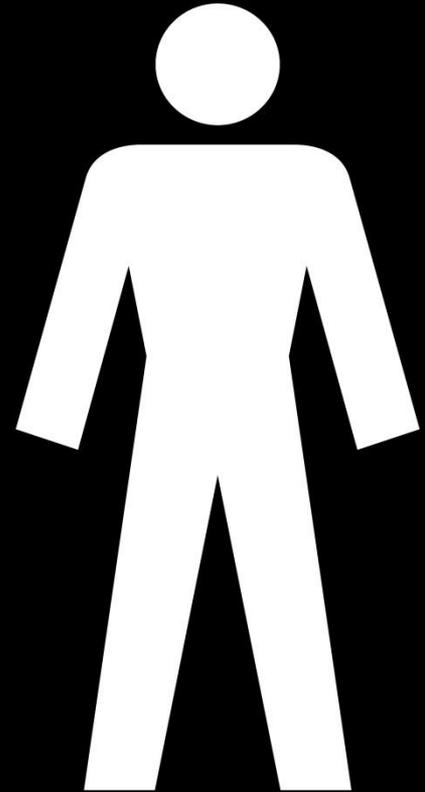
Recurrence / Relapse

- Devastation after a period of respite
- 'Unfairness'
- Depleted resources
- Failure of 'control' - helplessness
- No longer a 'historical event' – existential impact
- Treatment challenges (harder)
- Less support – “know the drill”
- Meaning of words like “palliative”

End of Life

- Differing meaning of death
- The ultimate fear of the unknown
- Impact on those left behind
- A difficult/painful death
- Loss of imagined future
- Denial?
- Planning, advanced directives, wills etc.
- Relief of suffering, release, acknowledgement

3) The Breadth of Impact: Going beyond Depression & Anxiety



Depression & Anxiety

Prevalence in Prostate Cancer (Watts et al. 2014)

- Depression: 17.3% pre Rx, 14.7% on Rx, 18.4% post Rx
- Anxiety: 27% pre Rx, 15% on Rx, 18.5% post Rx
- Anxiety generally more prevalent
 - E.g. advanced cancer rapid screening - 32.6% anxiety vs. 15.2% depressed (Roth et al. 1997)
- Most at risk for depressive symptoms include those with advanced disease, prominent cancer symptoms and side effects of treatment, and a history of clinical depression (Bennett & Badger, 2005)
 - BUT Rosenfield et al. (2004) - no significant associations were perceived between any stage of PC and psychological symptoms of depression
- Anxiety significantly associated with stage of PC [higher for advanced] (Johanes et al. 2013)
- Increased suicide risk for advanced vs. localised PC (Bill-Axelson et al. 2013)



**BUT THE PSYCHOLOGICAL IMPACT IS MUCH
BROADER THAN THIS...**

Adjustment

- Processes of adaptation that occur over time as people manage, learn from, and integrate changes that are precipitated by the altered circumstances of their lives (Brennan, 2001)
- Questioning of mental models across range of domains:

Life trajectory	Goals, aspirations
Attachments	Concern for dependants, need for attachments, systemic shifts / relationship changes)
Body	Sensation, reliability, disability, appearance, fertility, sexuality, dignity
Self, identity & worth	Self-esteem, control, power, autonomy, confidence, social identity
Existential beliefs	Confronting mortality, “why me?”, spiritual doubt or renewal, existential isolation

Adjustment

A shift in one's mental world, not just an absence of depression/anxiety

“Though anxiety & depression may return to premorbid levels, rarely does a cancer patient describe a sense of continuity with their lives before cancer - there is invariably a shift in the individual's sense of themselves & the world”

Distress

- May consist predominantly of depression, anxiety or anger or present as a mixed, broadly defined state (Graves et al., 2007)
 - Broader concerns included e.g. financial, spiritual, family concerns
- Lower perceived stigma (e.g. than depression) and broad acceptability to patients but not as well operationalised
 - *“multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment”* (NCCN, 2012)

Symptom Burden

- Varies between treatments
- Associations with anxiety/depression
 - e.g. 56% of PC men with erectile dysfunction found to be depressed (Shabsigh et al. 1998)
- Tendency to focus on frequency/presence
 - but which are most important/burdensome to the patient (psychological impact)
- **Sexual Dysfunction** Distress/Dissatisfaction
 - ~60% moderately to highly distressed re: dysfunction, loss of libido, orgasm difficulties
 - ↑ in younger (under 60) e.g. Cooperberg et al. (2003)
- **Incontinence**
 - Loss of confidence, avoidance of social situations (Weber et al. 2008)
 - ~30% bothered by urinary frequency at 5 years post-treatment (Potosky et al. 2004)

Illness Beliefs & Perceptions

- Illness beliefs – affect emotional and behavioural response to illness [Self-Regulation Theory; Leventhal, 1980]
 - i) identity applied to the illness and the symptoms associated with it
 - ii) perceived illness duration
 - iii) beliefs about the causes of the illness
 - iv) perceived consequences of the illness on one's personal life
 - v) beliefs about the extent to which the illness can be controlled by oneself or one's treatment
- Palliative care - Illness representations appear to be associated with depression independent of current functional or disease status (Price et al. 2012)
- Localised PC survivors - perceptions that PC was less comprehensible, was less likely to be controlled by treatment, and was more likely caused by one's own personality and behaviors associated with poorer emotional well being (Traeger et al. 2009)
- Advanced breast/gynae/lung cancer - patients' individual perceptions of cancer were better predictors of their quality of life than clinical characteristics of cancer (e.g., stage, illness duration) (Croom, 2012)
 - Echoes findings in breast of no significant relationship between objective disease severity (i.e. staging) and breast cancer patients' perceptions about the likely course of their disease (Rabin et al. 2004)

Coping Styles

- As a response to psychological impact e.g. avoidance
- “Fighting spirit” correlated with lower levels of anxiety and depression (Watson & Homewood, 2008)
 - Fighting spirit evidence more contentious in advanced cancer (O’Brien & Moorey, 2010)
- Some evidence that positive attitude and self-efficacy may be associated with better emotional adjustment (O’Brien & Moorey, 2010)
 - active, problem focused coping – adaptive
 - avoidant coping - maladaptive
- More ‘avoidant’ copers with PC [strategies deflected from a threat, such as substance use or self-distraction] have poorer physical and psychological outcomes than ‘approach’ copers [strategies directed towards a threat, such as planning or seeking information] (Roesch et al., 2005)
- Denial - normal adaptive process that permits an individual to cope with an otherwise unacceptable situation (Taylor 1983)
 - But potential impact on clinical outcomes ?
- Less than 20% correctly estimated the chance of treatment achieving cure, prolonging life, or palliating their symptoms – higher denial associated with increased misunderstandings (Gattellari et al. 1999)



Self-Image: Body

- Mismatch from expected body, body 'feminisation'
- Associated with significant reductions in quality of life and increased mental distress in prostate cancer (Cormie et al., 2014; 2016)
- ADT associated with worsening body image perception and resultant negative impact on quality of life (Harrington, 2011)
 - More self-image dissatisfaction than non-ADT patients
- ADT-induced changes in bodily appearance created emotional distance in spousal relationships (Navon & Morag 2003)
- But evidence of impact of body image impact in non-ADT groups as well (Langelier et al. 2018)
- Shame/Embarrassment e.g. urinary incontinence (fear of leaking, embarrassment from smell) or hot flashes

Self-image: Masculinity

- Feeling like less of a man
 - belief that they should be both physically and emotionally strong, invulnerable, in control, self-reliant, powerful, successful and sexually potent
- Low masculine self-esteem has been shown to contribute to increased anxiety, depression and cancer-specific distress in men with PC (Chambers et al. 2013)
- Implicated in men's reluctance to seek help for their emotional or sexual concerns after PC treatment (Wall & Kristjanson, 2005; Hyde et al. 2016, Oliffe, 2009)
- Terminology issues e.g. 'castration' (Pezaro et al. 2017) – punitive, animal connotations
 - Potential impact on wellbeing, communication and treatment decisions?

Neurocognitive change

- Cognitive domains e.g. executive function, attention, memory, language, visuomotor, visuospatial
- Limited research - can be challenging to assess with full neuropsychological batteries
- ADT in PC - higher rates of impaired cognitive performance over time relative to controls (Gonzalez et al. 2015)
 - performed significantly worse on visuomotor tasks than control (McGinty et al., 2014)
 - But some mixed findings in this area (e.g. Joly et al., 2006, Alibhai et al. 2010)

Perceived social support

- Tendency to focus on range (family, friends, other patients, healthcare professionals) or objective measures of support e.g. whether someone has a partner
- Also focus on positive (e.g. feeling heard, comforted, supported, positive feedback, problem-solving support etc.)
 - But negative indicators (e.g. over-protective behaviour, dismissive, conflictual behaviour patterns, pessimism)
- Less social support and a higher level of detrimental interactions (negative social support) were significant predictors of psychological co-morbidity in ambulatory PC patients (Mehnert et al. 2009)

Communication with Healthcare Profs

- Ambulatory PC patients reported medical treatment and doctor–patient communication to be most helpful in coping with their illness (above their partners) (Mehnert et al. 2009)
- Majority of prostate cancer patients avoid communication about cancer (due to low levels of perceived social support, fear of stigmatisation, reduction of horror caused by the diagnosis, and fear of being a burden) (Gray, 2000)

Relationship Quality & Intimacy

- Relationships
 - Breakdown in communication (e.g. differing coping styles) --- isolation, 'coping alone' --- associated with higher levels of distress (Manne et al. 2009)
- Side effects --- increased stress on couple, not initiating sexual contact, masculinity link
- Couples where PC patient reported erectile dysfunction reported less intimate contact, lower scores on togetherness and tenderness within the relationship (Müller et al. 2001; Riley & Riley, 2000)

Perceived Burden

- Perception of being a burden on others – increasingly common in advanced illness
- Advanced cancer - 77% were distressed about burdening others to at least some degree and 38% reported that they were 'moderately' to 'extremely' distressed about burdening others (Wilson et al. 2005)
- Evidence for impact on treatment decision-making

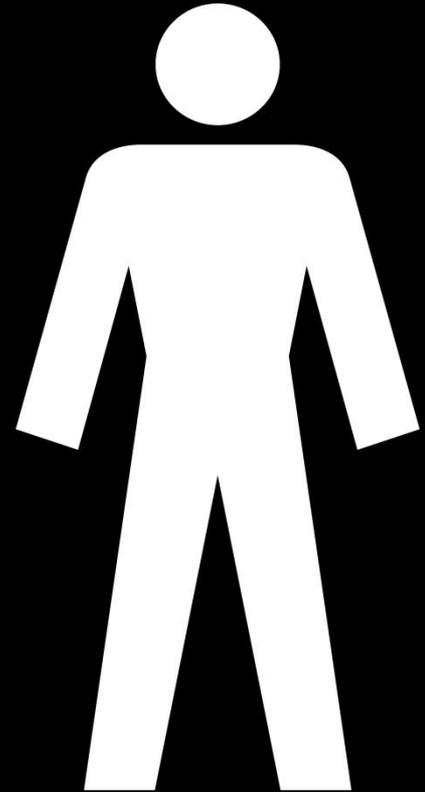
Decisional Regret

- mPC – 23% expressed regret about their treatment decision (Clark et al. 2001)
 - those who expressed regret more were more dissatisfied with their role in the decision making process
- No evidence of difference in decision regret level for early PC between treatments (Hurwitz et al. 2017)

Existential & Mortality Concerns

- What next?
 - Fears re: dying
 - Facing mortality
 - Loss/grief
 - Purpose/meaning
 - Interaction with spirituality
-
- Associated with stage of disease (Thorsteinsdottir et al. 2017)
 - ‘Demoralisation’ – comparable construct - can include self-perceived incapacity to deal effectively with specific situation (e.g. illness), loss of meaning, disheartenment, sense of failure, dysphoria
 - Distinct from emotional components of depression – motivation intact
 - 39.1% high levels of demoralisation in advanced cancer (Mehnert et al. 2011)

4) Assessing Psychological Need in Prostate Cancer



Psychological Support & the role of HCPs (NICE; 2004)

Improving Outcomes Guidance for Supportive and Palliative Care for Adults with Cancer

NCAT Peer Review Measures (2010)

Level 3/4

- 25% within 1 year of diagnosis (10% level 4, 15 % level 3)
- 10% of patients with advanced disease
- Carers
- Level 2 training/supervision

NICE four-tier model of psychological support in cancer care

Level	Group	Assessment	Intervention
1	All Health and Social Care Professionals	Recognition of Psychological Needs	Effective information giving, compassionate Communication and General Psychological Support
2	Health and Social Care Professionals with additional experience (e.g. Cancer Clinical Nurse Specialists)	Screening of Psychological Distress	Psychological techniques such as Problem Solving
3	Trained and accredited Professionals	Assessment of Psychological Distress and Diagnosis of some Psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental Health Specialists	Diagnosis of Psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Assessment – the use of Tools

Screening Tools for Anxiety/Depression

- PHQ-9/GAD-7

Holistic Needs Assessment (HNA)

- Normalises range of needs, permission-giving
- Particularly useful for less forthcoming (e.g. men!)

BUT

- Not knowing what to do or where to refer
- Concern about opening something up
- Timings (early distress is common/normal?)
- Is a checklist enough?

‘Normal’ Adjustment

What might a ‘normal’ adjustment look like?

- Everyone experiences some level of emotional and psychological response to cancer
- Cancer disrupts ‘normal’
- “Rollercoaster” of emotions
- Individuals differ
- It often takes time
- Each person in the family/system may have different journey

Getting 'Stuck' with Adjustment

Is distress enough?

Is this a reasonable response to the threat of cancer?

May include any or all of

- Distress beyond that which we might expect
- That has lasted for longer than we might expect
- That is impacting on the person's functioning or how they want to be living their life
- Where the reaction to the situation may actually be becoming part of the problem and/or making it worse

What we 'might expect'?

- Knowing your patient
- Asking

Looking out for... Low Mood / Depression

- Sadness/low mood
- Loss of appetite/weight
- Changes in sleep pattern
- Loss of enjoyment in things
- Loss of concentration
- Lack of energy/motivation
- Withdrawing socially/isolating self
- Irritability

- All 2 weeks +, causing impairment in functioning
- Key words:
 - “hopeless”, “pointless”, “worthless”, “low”
 - If they arise you MUST check suicide risk



Suicide Risk Assessment

Risk factors in Prostate Cancer

- Static - male, older, poor social support, limited treatment options (in advanced disease)
- Dynamic - pain, co-morbid mental illness/ co-existing chronic illness
- Some discussion (Fall et al 2009) about younger patients closer to diagnosis being at increased risk

General Principles

- Don't panic – it's ok to explore
- Establish rapport, develop a trusting relationship
- Use open questions, be present
- Establish the story around the suicidal ideation

Assessment

- Risk
 - E.g. mental health history, previous attempts, relationships, access to means
- Current intent/plans
 - E.g. desire to end life (beyond hopelessness), duration of thoughts/feelings, specific plans,
- Needs
 - E.g. protective factors (what is preventing them), coping strategies, care plan/contract



Looking out for... Anxiety

- Sleep disturbance
- Excessive worrying/racing thoughts
- Feelings of panic, restlessness or agitation
- Poor concentration
- Fear of the future
- Avoiding things

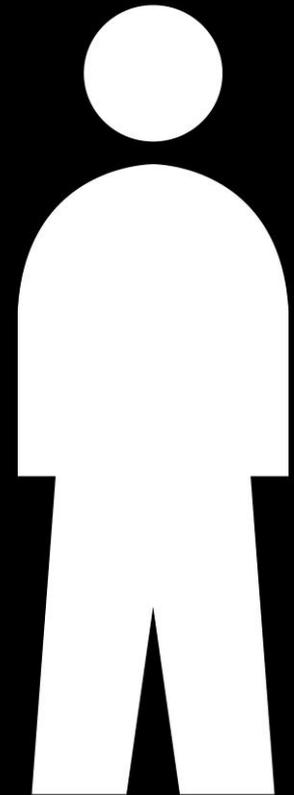
- All 2 weeks +, causing impairment
- Key words
 - “tense”, “wound up”, “panicky”, “butterflies”, “dread”, “restless”, “can’t relax”
 - Again, check the risk
- Verbal/non-verbal cues, less obvious signs e.g. avoidance, reassurance-seeking

Going Beyond the Assessment Tools

Enquire about the illness experience and psychological support needs – be curious!

<i>body</i>	<i>'how does that feel..'</i>
<i>doctors</i>	<i>'how did you get on with..'</i>
<i>treatment</i>	<i>'what was it like..'</i>
<i>cancer</i>	<i>'how do you understand..'</i>
	<i>'what did your doctors say..'</i>
	<i>'what did you ask about..'</i>
<i>consequences</i>	<i>'how did you recover..'</i>
<i>impact</i>	<i>'what does it mean for..'</i>
<i>ambivalence</i>	<i>'have you seen a psychologist/counsellor before?'</i>
	<i>'what would your thoughts be around that?'</i>

5) Intervention & Onward Referral



Eliciting & Tackling Concerns

“I know there is a problem, is it time to start fixing?”

KEY MESSAGES

- Good assessment is an intervention
- Identify **existing resource** before jumping in and assuming an onward referral is needed

Use **CHIPS**

- Who have you **CONFIDED** in?
- What's **HELPED** in the past?
- What can **I** as the patient do?
- What can the healthcare **PROFESSIONAL** do?
- **SUMMARISE**

The CHIPS Model

	EXAMPLES	AIM
Who have you CONFIDED in?	<i>“Who have you talked to about this?”; “Have you spoken to any friends, family or professionals about this?” “What are their views?”</i>	Identifying resources, Empowerment
What’s HELPED in the past?	<i>“What’s helped you cope with difficult times in the past?”</i>	Identifying resources, Empowerment
What can I as the patient do?	<i>“What can you do that might help you cope?”</i>	Identifying resources, Empowerment
What can the healthcare PROFESSIONAL do?	<i>“Is there anything you’d like me to do?”</i>	Support, Control
SUMMARISE	<i>“So it sounds like...”</i>	Dignity, Empathy



Level 2 Intervention Skills

Vary by regional training/supervision models

Commonly may include CBT-based skills/techniques:

- Relaxation – Deep Breathing
- Worry Management
- Distraction / Grounding
- Activity Scheduling
- Problem-solving
- Challenging Negative Thinking
- Basic Mindfulness Techniques

Referring On

Severity requires specialist input

- 'Stuck' (adjustment issues)
- Struggling with common psychological difficulties (e.g. anxiety/depression)
- Functional impairment
- Not resolving over time and/or with your intervention

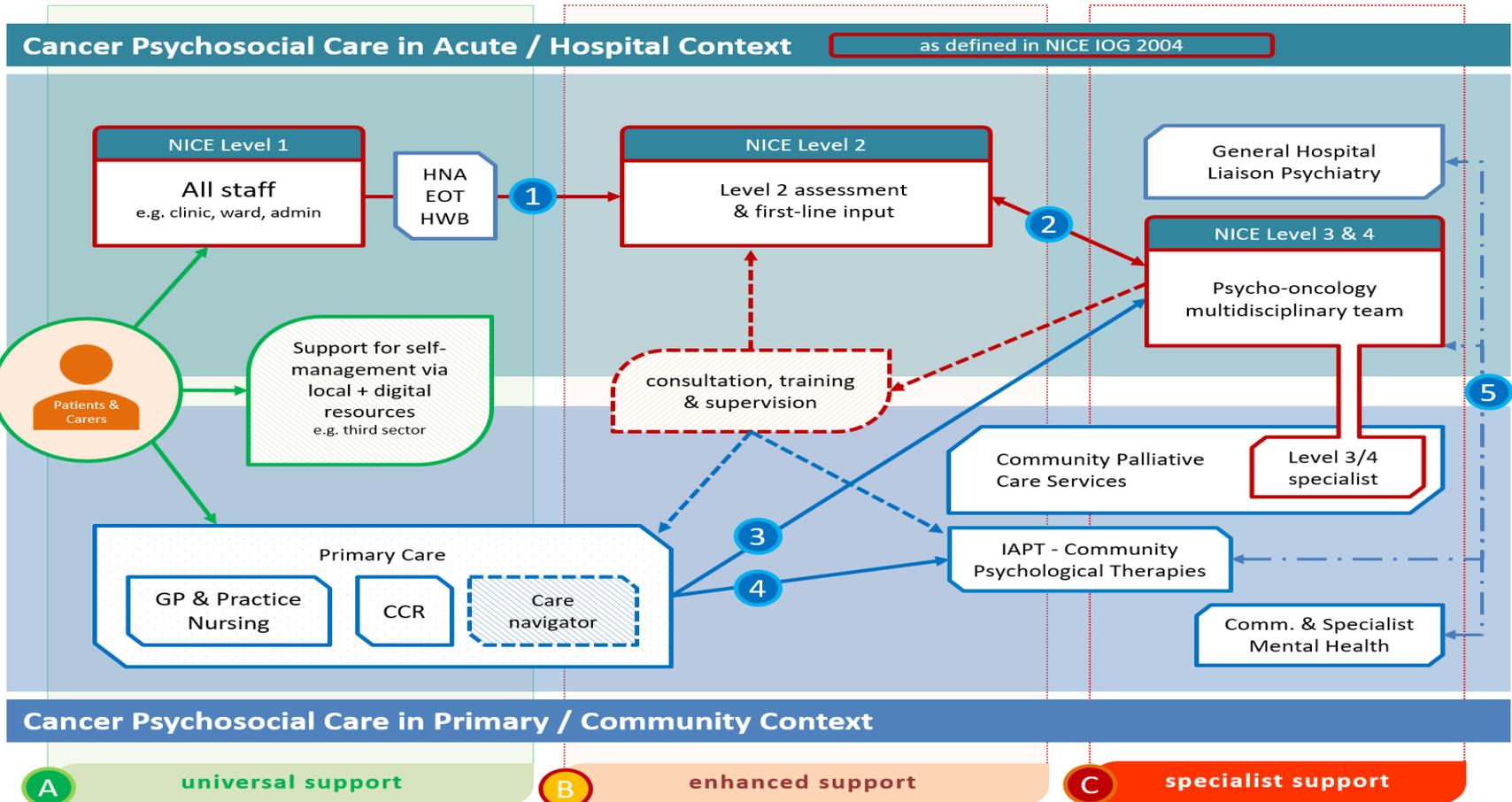
Complex issues

- end-of-life issues, suicidality, trauma, body image/visible difference issues, panic, phobias, obsessive compulsive behaviours, substance abuse, relationship difficulties, aggression

Treatment-interfering behaviours

- decision-making difficulties, treatment refusal, adherence issues, capacity issues, side-effect management (pain, fatigue)

Onward Referral: Where to send?



Level 3/4 Psychological Approaches

- Integrated Psycho-oncology vs. Primary Care considerations
- Individual (vs. Group)
- Psychiatric Management (commonly community/GP)

Evidence-based Psychological Approaches

- Cognitive Behavioural Therapy
 - Acceptance & Commitment Therapy
 - Mindfulness-based Approaches
 - Solution-Focused Therapy
 - Cognitive Analytic Therapy
 - Couples & Family Therapy
 - Motivational Interviewing
 - Narrative Therapy
 - Counselling
-
- Evidence of efficacy e.g. Vartolomei et al. (2018)
 - Most PCa studies in CBT and couples-based therapies
 - Evidence with carers e.g. Borki et al. (2017)

Additional Referral Considerations

- Carers
- Community Mental Health Teams
- Community Palliative Care
- 3rd Sector Organisations
- Broader Psychosocial approaches
 - Support groups
 - Peer support
 - Complementary therapies

YOUR Psychological Wellbeing

“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”

—Rachel Remen. *Kitchen Table Wisdom: Stories that Heal*. New York: Riverhead Books, 1996.



Men United.
Keeping friendships alive.