

Managing the toxicities of castration-based therapy and holistic support for men with advanced disease

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Castration-based therapy

- Usually given in the form of depot injections of an LHRH agonist
- Antagonists and orchidectomy also used
- In advanced prostate cancer they are usually a treatment for life
- These are drugs/ treatments, with side effects that can affect the quality of life and/or survival of prostate cancer patients



ADT side effects

Body feminisation

- Genital shrinkage
- Gynecomastia
- Mastodynia
- Weight gain/ body fat redistribution
- Loss of muscle mass
- Loss of body hair
- Hot flushes

Sexual changes

- Erectile dysfunction
- Loss of sexual interest
- Genital shrinkage
- Fatigue
- Orgasm/ ejaculation changes

Cognitive and affective disturbances

- Depression
- Impaired memory and attention
- Fatigue
- Increased emotionality and tearfulness

Metabolic changes

- Risk of developing osteoporosis
- Subsequent increased risk of fracture and associated morbidity and mortality
- Weight gain (mostly as fat)
- Risk of developing insulin resistance
- Increased risk of cardiovascular disease and diabetes



Approaches to toxicities

- Ignore the problem?
- Minimise the problem?
- Fix the problem?
- Minimise impact?
- Help adapt to change?



Managing toxicities and holistic support for men with advanced disease



Assessment and asking the questions

- In consultations
- Support groups
- Seminars/ health and well being events
- Holistic needs assessment

Holistic Needs Assessment

INSTRUCTIONS: For each item below, please tick YES or NO if they have been a concern for you during the past week (including today). Please also tick DISCUSS if you wish to speak about it during your appointment.

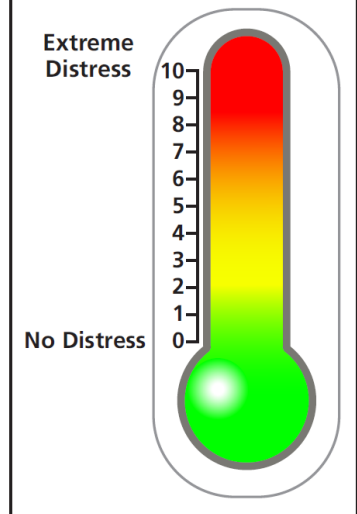
Concerns Thermometer

" I am coping well"

Yes

No

Please circle the number that best describes how much distress you have been feeling in the last week, including today.



OFFICE USE ONLY

Patient ID:

Preferred name:

Pathway stage:

Date:

Staff ID:

Practical Concerns

	Yes	No	Discuss
Caring responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing or Finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport or parking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work or education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information Needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Family Concerns

Relationship with children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Emotional Concerns

Loneliness or isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worry, fear or anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anger, frustration or guilt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory or concentration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hopelessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty making plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Spiritual Concerns

Loss of faith or other spiritual concern	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of meaning or purpose in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Regret about the past	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Physical Concerns

	Yes	No	Discuss
High Temperature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wound Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Passing Urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation or Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Indigestion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea or vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating or appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in taste	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sore or dry mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling swollen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breathlessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dry, itchy or sore skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tingling in hands or feet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hot flushes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing or dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moving around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other medical condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Adapted with permission from the **NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management (V.3.2012)**. © 2012 National Comprehensive Cancer Network, Inc. Available at: NCCN.org. Accessed [25th May 2012] To view the most recent and complete version of the NCCN Guidelines®, go on-line to NCCN.org

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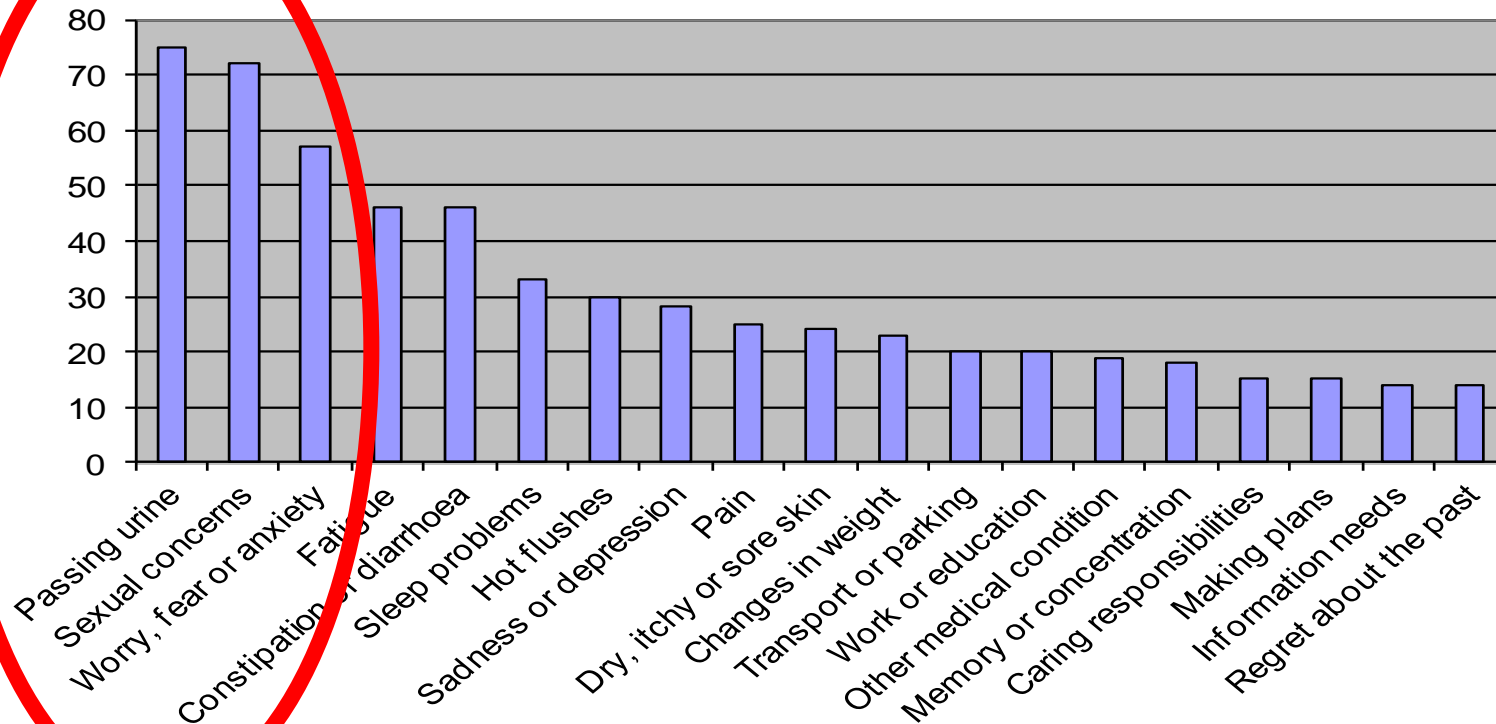


HNAs

- Not ADT or prostate specific
- But does cover broadly sexual issues, relationship issues, cognitive changes
- May provide a framework
- Focus on effects of treatment (patient focus rather than disease)

Concerns reported in HNAs

Top 20 concerns Jan-June 2015



Assessing the impact

- People vary greatly on how they interpret physical side effects.
- What is worse?
 - Hair loss?
 - Gynecomastia?
 - Mastalgia?
 - Erectile dysfunction?
 - Loss of libido?
 - Loss of mental sharpness
 - Weight gain?



No validated questionnaire or survey instrument that can be used to predict who will find which changes most and least distressing.

ADT side effects

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Specific advice



Metabolic changes

- Dyslipidaemia
- Insulin resistance & Diabetes
- Obesity (central fat and loss of muscle mass)
- Osteoporosis

Lifestyle measure in the management of cardiovascular and osteoporosis risk

Lifestyle measure	Osteoporosis	Cardiovascular disease/ metabolic syndrome
DIET	Diet high in calcium and vitamin D	Diet low in saturated fats and high in fibre
EXERCISE	Resistance exercise	Aerobic exercise
WEIGHT	Healthy BMI	Healthy BMI
SMOKING	Advise smoking cessation	Advise smoking cessation
ALCOHOL	Moderate intake	Moderate intake

Recommendations to Prevent Bone Loss (National Osteoporosis Foundation <http://nof.org/learn/prevention> accessed 5th February 2014)

Recommendations to reduce cardiovascular risk (British Heart Foundation www.bhf.org.uk/heart-health/prevention/healthy-eating.aspx accessed 5th February 2014)

Body feminization

- **The American Cancer Society claims that...** “Men who no longer have their testicles or who are on hormone therapy drugs often feel like ‘less of a man.’ *This is a myth. **Manhood does not depend on hormones, but on a lifetime of being male.***”

From: *Sexuality and Cancer: For the man who has cancer and his partner.* American Cancer Society, 2009.

Body feminization

- ADT often challenges men's core identity, leaving many...**feeling like they are at the border of masculinity**: not fully masculine nor feminine, but undefined

“Whenever I saw my body, I wondered, ‘Who am I? A woman? A man? It’s a very confusing situation. I believe I’m neither one thing nor another; that’s the only way I can think about myself without becoming confused. To tell the truth, at first, every time I looked at myself [in the mirror] I became depressed.”



Body feminization

- Listen for the cues
- Acknowledge
- Listen
- Assess impact
- Adaptation, acceptance and some problem solving

Body feminization

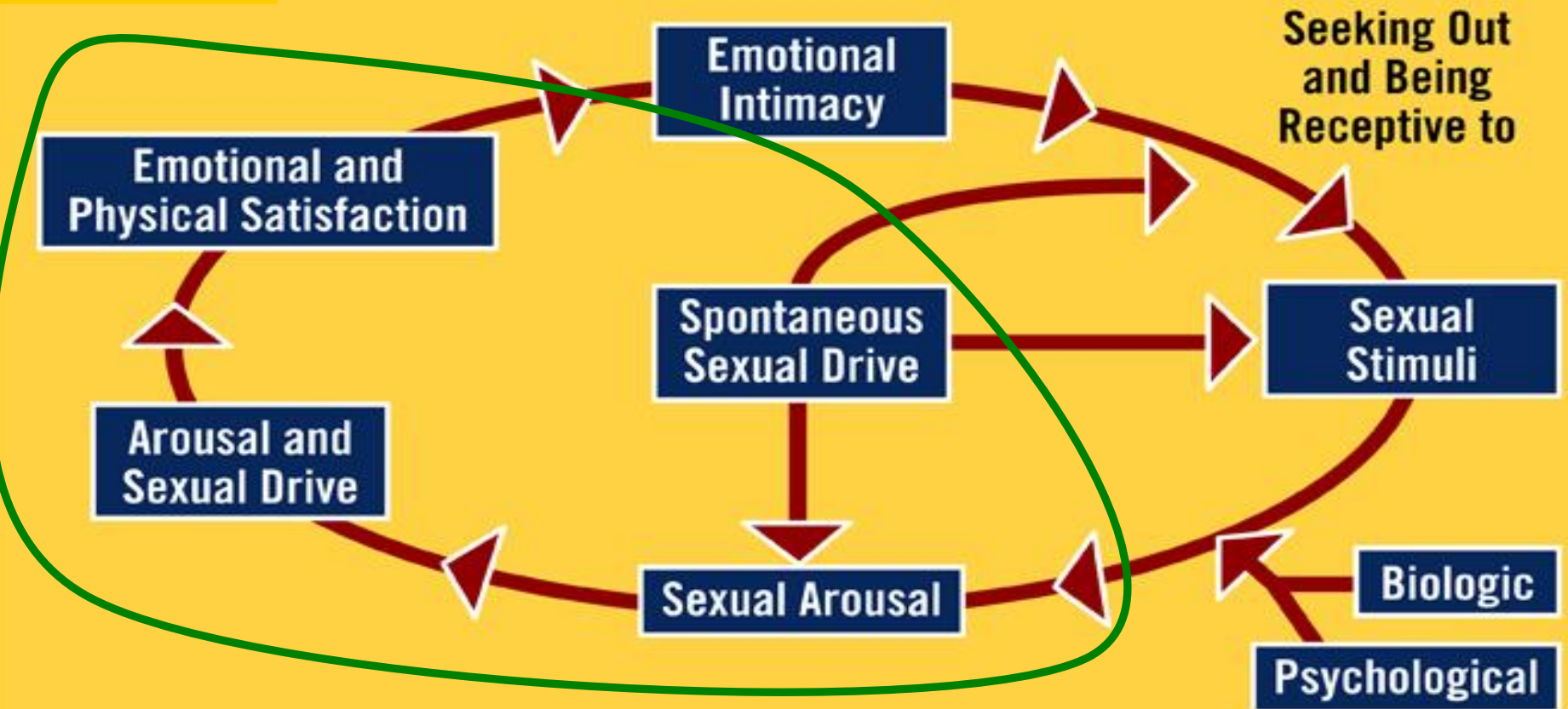
Gynaecomastia and mastodynia	<ul style="list-style-type: none">■ Preventive management through radiation treatment■ Binding/camouflage■ Selective oestrogen receptor modulators (e.g. tamoxifen)■ Mastectomy/liposuction
Weight gain and loss of muscle mass	<ul style="list-style-type: none">■ Increased physical activity■ Also may have impact on mood
Hot flushes	<ul style="list-style-type: none">■ Identifying and modifying trigger factors■ Medroxyprogesterone, CPA, SSRIs, venlafaxine,■ Diaphragmatic breathing/paced respiration■ Visualisation/ relaxation
Genital shrinkage	<ul style="list-style-type: none">■ Pharmacological and physical ED treatments (e.g. VCD)

Sexual changes with ADT

- Most men on ADT experience nearly complete loss of sexual interest.
- ~15% still report being sexually active at some level—and are capable of having orgasms even without erections
- Sole focus on erections is unlikely to be successful and may make problem worse
- Communication: what do you want?
- Adaption to change and acceptance
- Moving forward



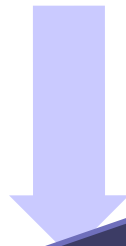
Sexual Response Cycle



Basson R. *Med Aspects Hum Sex*. 2001;41-42. Basson R. Human sex-response cycles. *J Sex Marital Therapy*. 2001;27:33-43. Adapted with permission.

Kingsberg SA, Knudson G.

COMMUNICATION



Acceptance that sex
no longer part of
relationship/life

Adaptation to age
related changes

**Recognition that there is a loss
which may need to be
acknowledged**

Exploring different
ways achieving
sexual satisfaction

Erection restoring
treatments (but only
once above
addressed)

Sexual changes

Erectile dysfunction	<ul style="list-style-type: none">■ Standard pharmacologic and physical ED treatments■ An ED treatment that is not fully effective but only partially effective can do more harm than good. It can erode a patient's confidence in his sense of virility and masculine capability■ Redefinition or reframing of sexual activities (e.g. non-penetrative sexual activity)■ Renegotiated or novel sexuality
Loss of sexual desire	<ul style="list-style-type: none">■ Special effort to enhance displays of physical affection■ Counselling to recruit past sexual fantasies and explore expanding erogenous zones■ Use of erotic material to enhance sexual arousal
Delayed or absent orgasm	<ul style="list-style-type: none">■ Use of lubricants for increased stimulation without skin irritation■ Use of vibrator/sex toys to combat fatigue■ Reframing of the sexual experience — shared intimacy rather than focus only on reaching orgasm (sensate focus)
Infertility	<ul style="list-style-type: none">■ Assess importance for all patients regardless of age■ Sperm banking for those interested



Sexual changes: our issues

- Health professionals willingness to discuss
- Embarrassment of lack of knowledge
- The setting in which these ideas are presented to them (i.e., in a clinic room, in a sexual function clinic, or at a non-clinical sex workshop)

Cognitive and affective symptoms

Depression	
Changes in emotionality	■ Counselling
Tension, anxiety, fatigue and irritability	■ Exercise
Decline in spatial reasoning, spatial abilities and working memory	■ Pharmacological therapies
	■ Support (peer, family, professional)
	■ Relaxation and stress management techniques
	.

Other changes

Relationship changes	<ul style="list-style-type: none">■ Counselling to aid couple's adjustment■ Increased effort toward emotion and physical connectedness■ Patient and partner education about potential relational consequences/challenges before starting ADT
Fatigue and sleep disturbances	<ul style="list-style-type: none">■ Exercise■ Counselling■ Relaxation techniques

ADT and holistic support for men with advanced disease

■ Giving information and support

- When
- Where
- Who
- How
- How often
- Different for all



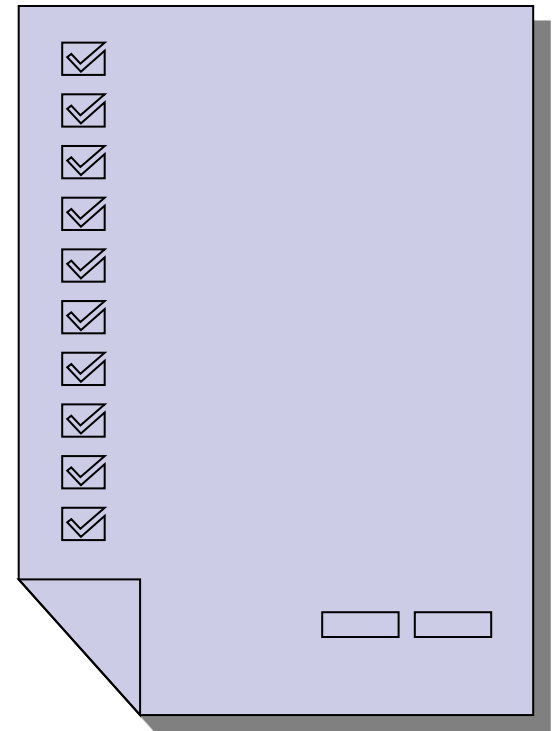
ADT and holistic support for men with advanced disease

- Health and wellbeing
 - Diet
 - Exercise
 - Benefits include metabolic but also psychological
 - Relaxation
 - Stress management
 - Provide peer support
 - Introduce MDT
- Referral when necessary
 - Psychologist
 - Dietician
 - Physiotherapist
 - Counsellor
 - Sex therapist
 - Chaplain
 - Local groups

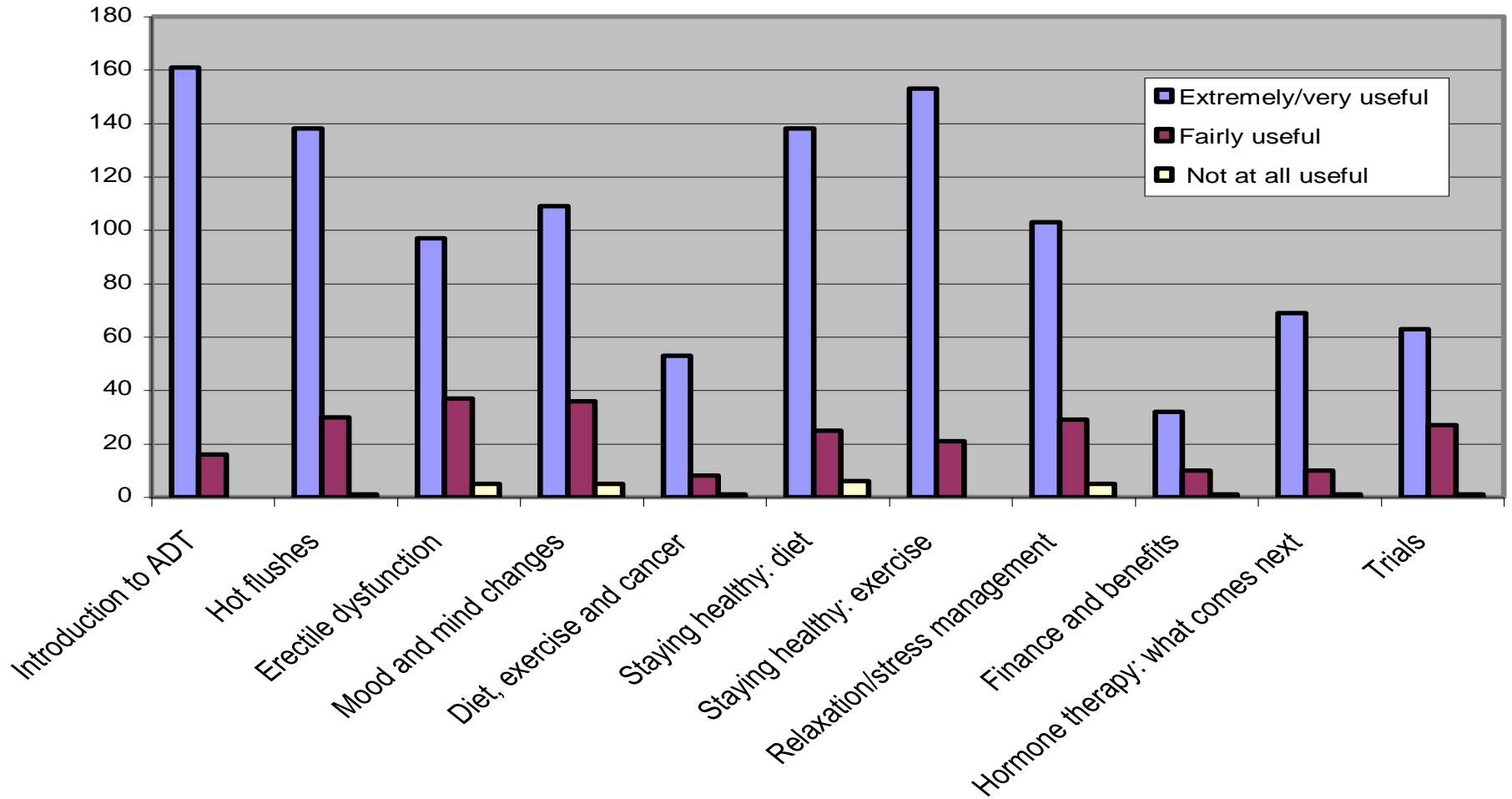
09.30-1000	Tea and registration
10.00-10.30	Introduction to Hormone therapy and side effects
10.30-11.00	Managing hot flushes
11.00-11.30	Erectile dysfunction
11.30-11.50	Tea break
11.50-12.35	Managing mood and mind changes
12.35-12.50	Trials and the biobank
12.50-13.00	Ask the Panel
13.00-13.45	Lunch
13.45-14.15	Staying healthy: Diet
14.15- 14.45	Staying healthy: Exercise
14.45-15.15	Finance and benefits
15.15-16.00	Tea/coffee
16.00-16.30	Hormone therapy...what comes next?
16.30-17.00	Relaxation and stress management
17.00	Questions and close

Evaluation

- A total of 191 men and 45 friends/partners have attended the seminars
- 180 evaluations were completed (157 men with prostate cancer and 23 partners)



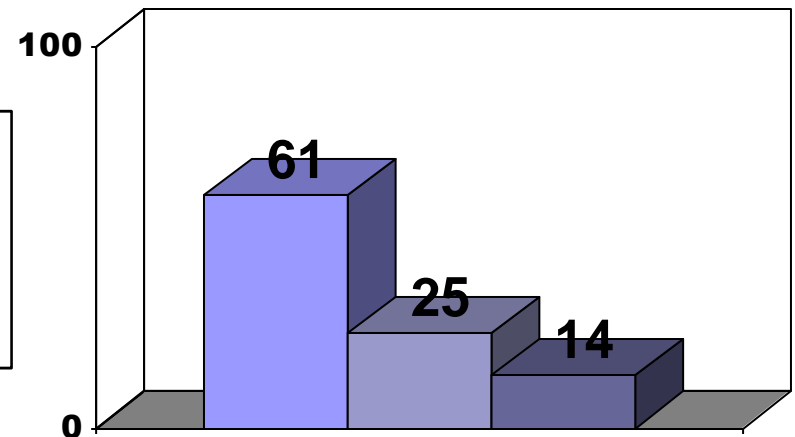
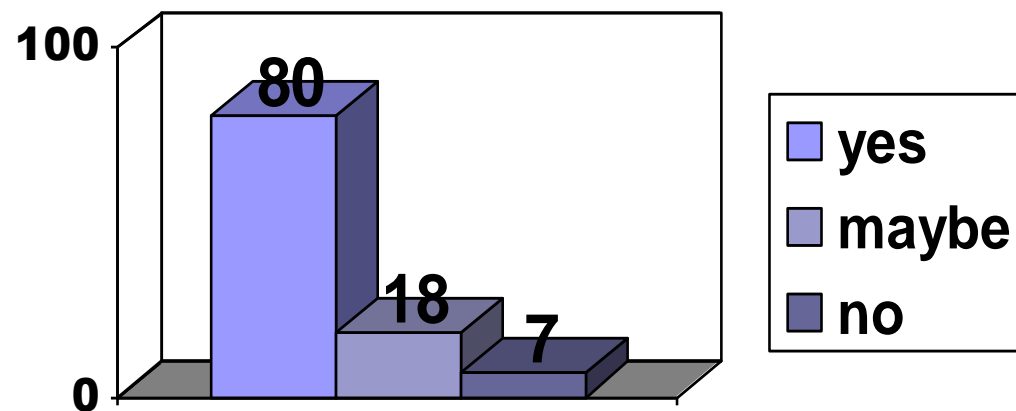
Evaluation of sessions



Evaluation: making changes

- Patients were asked whether they thought that the seminar would make them change their **exercise habits**

- Patients were asked whether they thought that the seminar would make them change their **diet**



All responders said that they would recommend the seminar to other men on ADT.

I am so glad that there are things I can do to feel better

Excellent- I would recommend to everyone

I cried when I heard that other people were going through the same things as we were

I understand so much more about my treatment and feel much less scared now

I think everyone should have this at the start of treatment

I was too embarrassed to ask questions myself but I was able to listen to all the other men and learnt so much

This has put years on my life expectancy



Summary: key principles

- Be proactive
- Be aware of cues and respond to them
- Affects more than the man (remember the wider network including partners and family)
- Different people need different approaches: do we have different models of support and help?
- Think about timing, setting and delivery of your information
- Be truthful yet positive

Summary: key principles

- ADT side effects can affect the way a man views his whole self, so needs a whole person approach
- May involve strategies to promote adaptation to change just as much as quick fixes

