Supportive care: *an overview*

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The University Of Sheffield.

NHS
National Institute for Health Research

Overview

- Definitions
- Models
- Implications for palliative care
- Challenges

First, what is *“Palliative Care”?*

NICE, 2004:

‘Palliative care is the active holistic care of patients with advanced, progressive illness.

Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.

The goal of palliative care is achievement of the best quality of life for patients and their families.

Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.’

Why is it called ‘palliative care’?

- ‘Palliative care’ was first used a euphemism for ‘hospice care’ in French speaking Canada (Montreal), because ‘hospice’ meant ‘an old peoples home’
- There is still confusion in the English-speaking world about what ‘palliative care’ means
- Many still use it as a euphemism for end of life care

A new international framework for palliative care

S.H. Ahmedzai [a,*,1], A. Costa [b], C. Blengini [c], A. Bosch [d], J. Sanz-Ortiz [e], V. Ventafridda [c], S.C. Verhagen [f], on behalf of the international working group convened by the European School of Oncology [1]

Eur J Cancer 2005

- Palliative care is the person-centred attention to physical symptoms and to psychological, social and existential distress and cultural needs in patients with limited prognosis, in order to optimise the quality of life of patients and their families or friends.

‘Hospices are not only for the dying’ –
but public and many professionals don’t always see that

Why has palliative care focused on end of life?

- Reflects 150 years history of palliative care development
- Dying is handled poorly in Western societies
- Pain and other types of suffering can increase at the end of life
- Humane need for society to care for its dying people

Palliative care and ‘total pain’ *(Cicely Saunders)*

Total pain –

- Physical pain
- Emotional pain
- Social pain
- Spiritual pain
- Financial pain...

Importance of family

- Effects on quality of life
- Effects on carers and children
- Economic factors…..

Humanity of symptom control

- BUT - For many (most?) chronic diseases, symptom palliation is the best that medicine can offer, sometimes with prolongation of life
- We need to give symptom palliation as much time and care as we give to diagnosing and treating disease
- Is it not humane to care for pain and suffering in all people, not only those who are dying?

J Clin Oncol 2017

Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update

Betty R. Ferrell, Jennifer S. Temel, Sarah Temin, Erin R. Alesi, Tracy A. Balboni, Ethan M. Basch, Janice I. Firn, Judith A. Paice, Jeffrey M. Peppercorn, Tanyanika Phillips, Ellen L. Stovall,† Camilla Zimmermann, and Thomas J. Smith

"Early palliative care"

- What about 'early palliative care' (EPC)?
- ASCO guideline based on past 7 years of studies of EPC
  - Most in USA
  - Most in cancer
  - Most in 'advanced' stage of cancer

Recommendations: "Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment."

"Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may offer family and friend caregivers of patients with early or advanced cancer to palliative care services."

Evolution of oncology

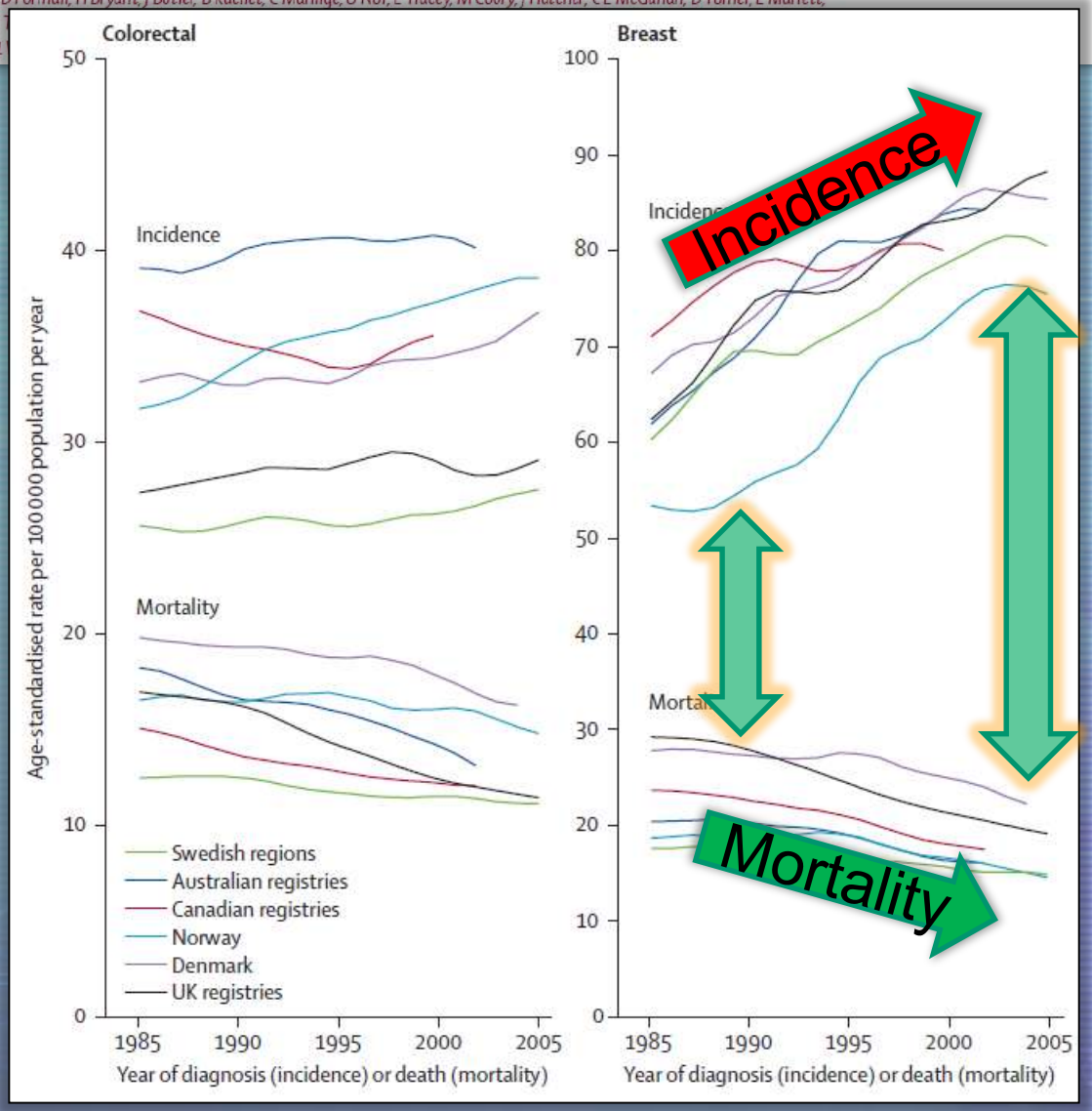
Original aims	Modern aims
Diagnosis	Prevention
Cure	Early and accurate diagnosis
Palliation	Cure
	Prolonging life
	Palliation
	Rehabilitation
	End of life care

Rise of survivorship

Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data

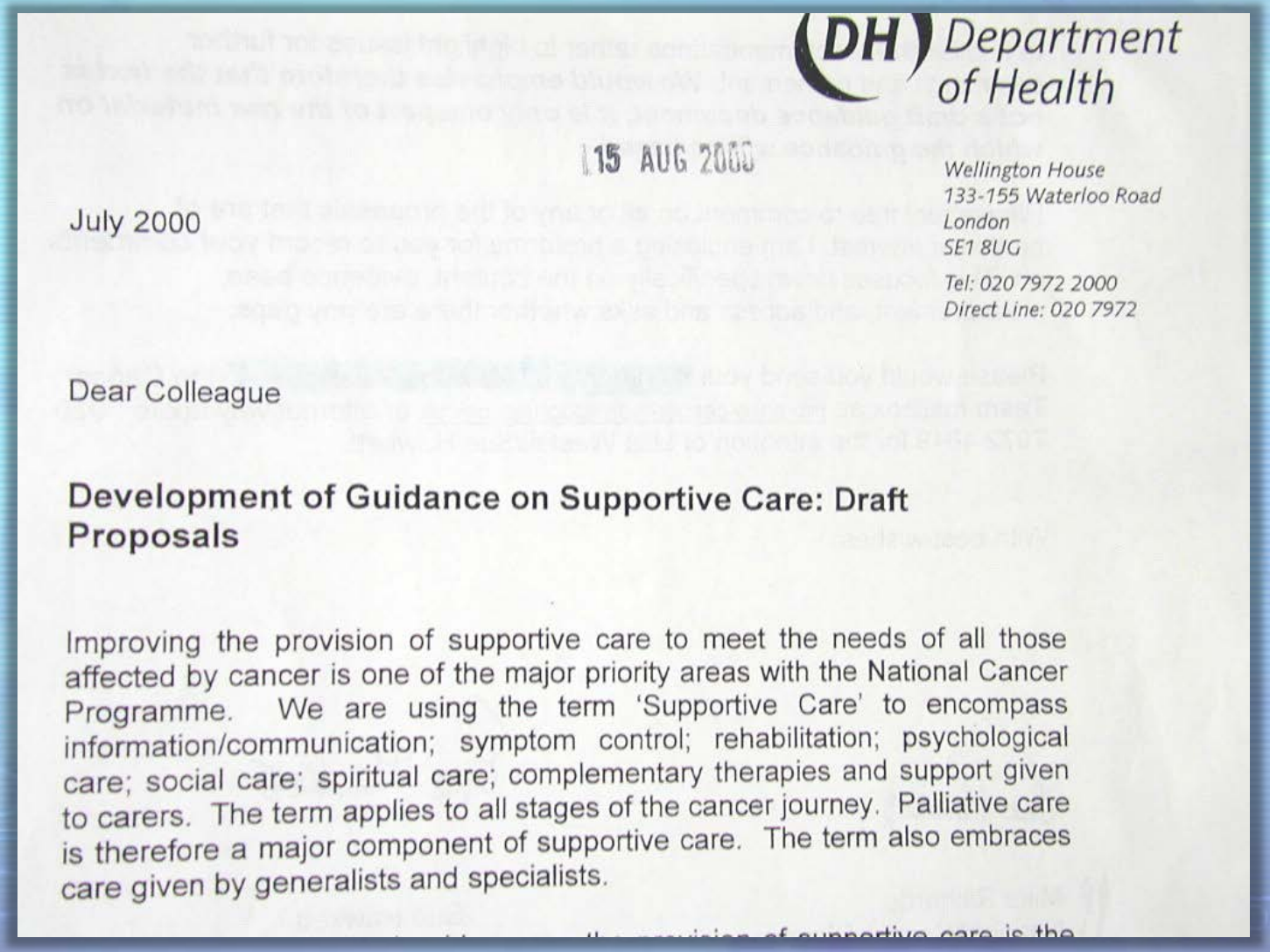
Lancet 2011

M P Coleman, D Forman, H Bryant, J Butler, B Rachet, C Maringe, U Nur, E Tracey, M Coory, J Hatcher, C E McGahan, D Turner, L Marrett, M L Gjerstorff, T
ICBP Module 1



Increasing cancer incidence
+ decreasing mortality
= more survivors

First UK mention of ‘Supportive care’ - 2000



DH Department of Health

15 AUG 2000

Wellington House
133-155 Waterloo Road
London
SE1 8UG

Tel: 020 7972 2000
Direct Line: 020 7972

July 2000

Dear Colleague

Development of Guidance on Supportive Care: Draft Proposals

Improving the provision of supportive care to meet the needs of all those affected by cancer is one of the major priority areas with the National Cancer Programme. We are using the term ‘Supportive Care’ to encompass information/communication; symptom control; rehabilitation; psychological care; social care; spiritual care; complementary therapies and support given to carers. The term applies to all stages of the cancer journey. Palliative care is therefore a major component of supportive care. The term also embraces care given by generalists and specialists.

'Supportive care' in cancer

MASCC definition:

"The prevention and management of the adverse effects of cancer and its treatment.

This includes physical and psychosocial symptoms and side effects across the entire continuum of the cancer experience including the enhancement of rehabilitation and survivorship."

NICE (2004) defined “Supportive care”

‘helps the patient and their family to cope with cancer and treatment of it –

from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement.

It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

..given equal priority alongside diagnosis and treatment.’

NICE (2004) Supportive Care Guidance

Topic Areas

1. Co-ordination of care
2. User involvement in planning, delivering and evaluating services
3. Face-to-face communication
4. Information
5. Psychological support services
6. Social support services
7. Spiritual support services
8. General palliative care servic[illegible] of dying patients
9. Specialist palliativ[illegible]
10. Rehabil[illegible]
[illegible] therapy services
1[illegible]vices for families and carers, incorporating bereavement care
13. Research in supportive and palliative care: current evidence and recommendations for direction and design of future research

Depends on needs – NOT the stage of disease

The multiprofessional supportive care ‘virtual team’

- Palliative medicine
- Specialist nursing
- Physiotherapy
- Social work
- Chaplaincy
- Pharmacy

- Psychology
- Dietician
- Occupational therapy
- Speech therapy
- Complementary therapies

- Oncology, surgical, medical specialties
- Primary care team
- Pain Clinic
- Patient & public information

An unhelpful description

CANCER RESEARCH UK

Let's beat cancer sooner

HOME | ABOUT CANCER | SUPPORT US | OUR RESEARCH | FUNDING FOR RESEARCHERS | ABOUT US

Home › About cancer › Find a clinical trial › A trial looking at chemotherapy for frail or elderly patients with advanced cancer of the stomach or food pipe (GO2)

A trial looking at chemotherapy for frail or elderly patients with advanced cancer of the stomach or food pipe (GO2)

This trial is trying to find the best way to treat people with cancer of the stomach or cancer of the food pipe (oesophagus) who are not strong enough to have standard chemotherapy. The trial is supported by Cancer Research UK.

Doctors often treat advanced cancer of the stomach or food pipe with chemotherapy. A combination of drugs called epirubicin, oxaliplatin and capecitabine (EOX) is a type of chemotherapy they often use.

For some people, chemotherapy with 3 drugs is too strong, but a milder form of chemotherapy may still be helpful. For others, it may be best not to have chemotherapy at all, but to have other treatments to control cancer symptoms. This is called best supportive care. There is currently no way for doctors to be sure what will be the best treatment for each individual patient.

Implementation of supportive care and best supportive care interventions in clinical trials enrolling patients with cancer†

Annals Oncol 2015

R. T. Lee[1*], K. Ramchandran[2,‡], T. Sanft[3] & J. Von Roenn[4]

'Best supportive care' trials

Systematic review of the literature for clinical trials published between 1980 and 2012 in which systemic anticancer therapy was compared with an SC-only arm and compared SC implementation with World Health Organization (WHO) published guidelines.

Table 1. Comparison of therapies included in the definition of SC versus BSC

Category	All *N* (%)	SC *N* = 25	BSC *N* = 48	*P*-value
Analgesics	34 (47%)	13 (52%)	21 (44%)	0.50
Radiation therapy	32 (44%)	13 (52%)	29 (40%)	0.31
Antibiotics	20 (27%)	3 (12%)	17 (35%)	0.033
Steroids	19 (26%)	10 (40%)	9 (19%)	0.05
Blood transfusions	19 (26%)	1 (4%)	18 (38%)	0.002
Psychological support	13 (18%)	4 (16%)	9 (19%)	0.77
Nutritional counseling	12 (16%)	2 (8%)	10 (21%)	0.16
Social work	9 (12%)	4 (16%)	5 (10%)	0.49
Antiemetics	8 (11%)	2 (8%)	6 (13%)	0.56
Antidepressants/anxiolytics	4 (5%)	3 (12%)	1 (2%)	0.077
Palliative specialist	2 (3%)	2 (8%)	0	0.047
Spiritual support	1 (1%)	0	1 (2%)	0.47
Other therapies (e.g. thoracentesis, pleurodesis)	12 (16%)	2 (8%)	10 (21%)	0.16

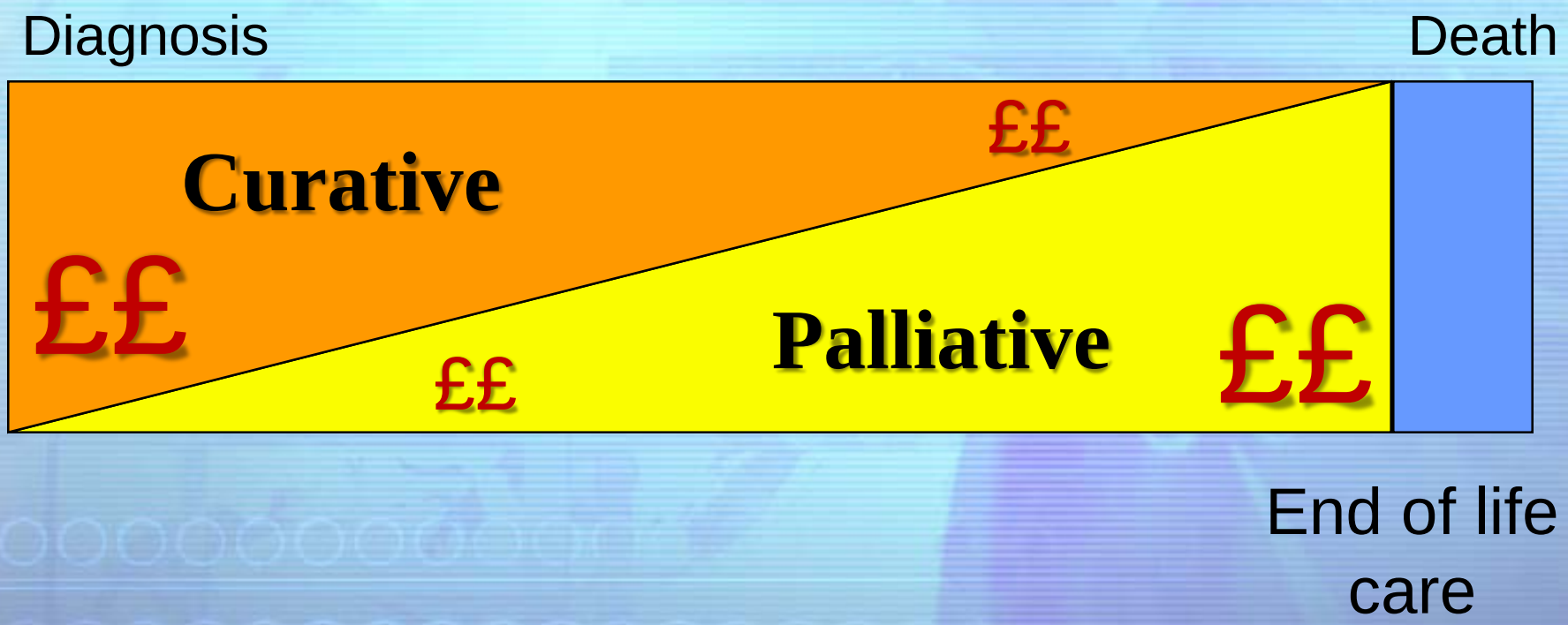
Another unhelpful concept

Cure ⟷ Care

(Curative) (Palliative)

courtesy: Robert Pope

20th century view of cancer care – the WHO resource allocation model



Development of a generic working definition of 'supportive care'

BMJ Supp Pall Care 2013

Fiona Cramp,[1] Michael I Bennett[2]

Delphi study with 37 experts and 96 charities

SC aims to:

- Control the symptoms that occur as a result of the condition or its treatment and prevent complications thus allowing the individual to tolerate and benefit from active therapy more easily
- Meet a patient's spiritual, practical, physical, social, psychological, sexual and cultural needs
- Inform patient decision making and optimise patient understanding in relation to the illness and its treatment
- Enhance health professional–patient communication
- Improve general physical and mental health
- Optimise patient comfort and ease the physical burden of the condition thus in turn improving the ability to function and reducing the impact of disability
- Help the patient and their family cope with their illness and the treatment of it
- Empower the patient and their family as well as promoting self-help and user involvement thus enabling the individuals to draw upon their own strengths.

Development of a generic working definition of 'supportive care'

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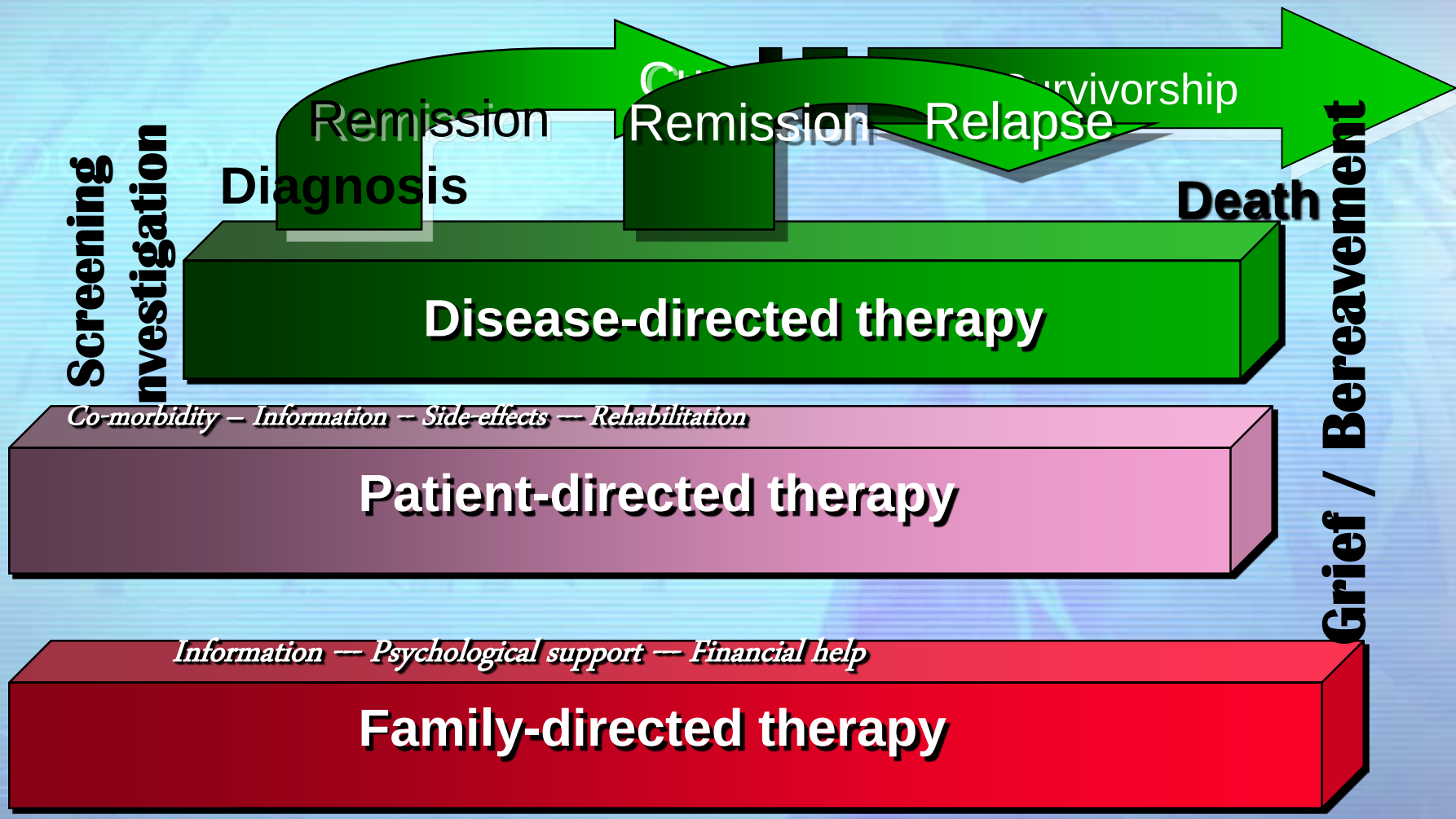
SC may include the following, as needed:

- Issues of survivorship, palliation and bereavement
- Support groups
- Professional counselling and psychotherapy
- Rehabilitation
- Practical help
- Benefits advice
- Pharmacological and non-pharmacological interventions
- Nutritional support

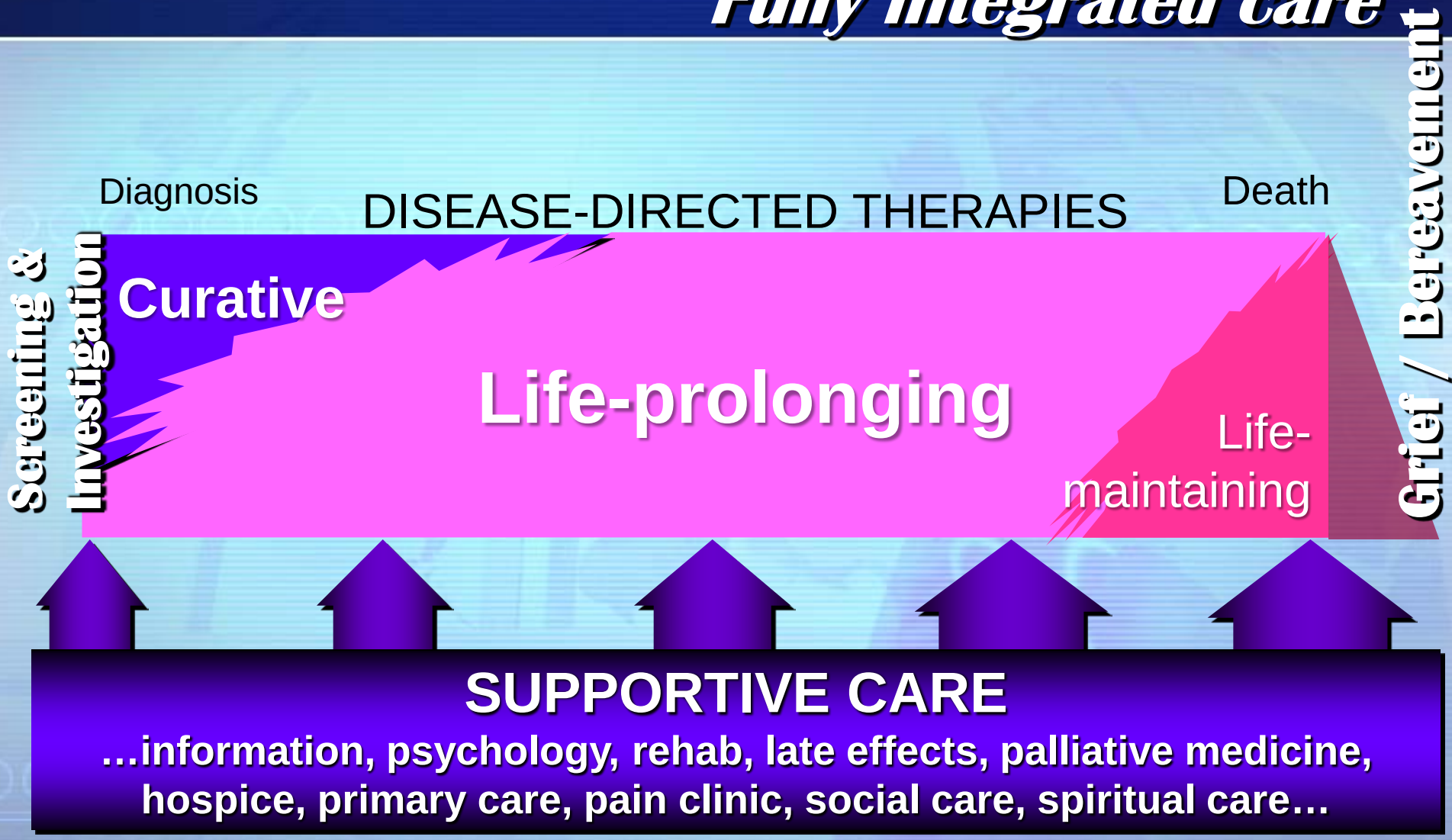
Sheffield model of supportive care - Total patient and family experience



Adapted from: Ahmedzai, Walsh *Seminars in Oncol* 2000

Sheffield model of supportive care

Fully integrated care



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Definition of supportive care: does the semantic matter?

David Hui

Curr Opin Oncol 2014

KEY POINTS

- Although wide variations exist among the definitions for supportive care, all of them include elements of symptom management and improvement of quality of life for cancer patients on treatments and those with advanced diseases.
- Primary supportive care is delivered by oncologists and primary care teams, providing basic symptom management and information in the front-line setting.
- Secondary supportive care is provided by teams with specialized expertise, such as palliative care, wound care, and psychiatry, on a consultation basis.
- Randomized controlled trials involving a 'supportive care' arm should clearly define the level of intervention and ideally involve secondary supportive care services to ensure a high standard of care delivery.

Definition of supportive care: does the semantic matter?

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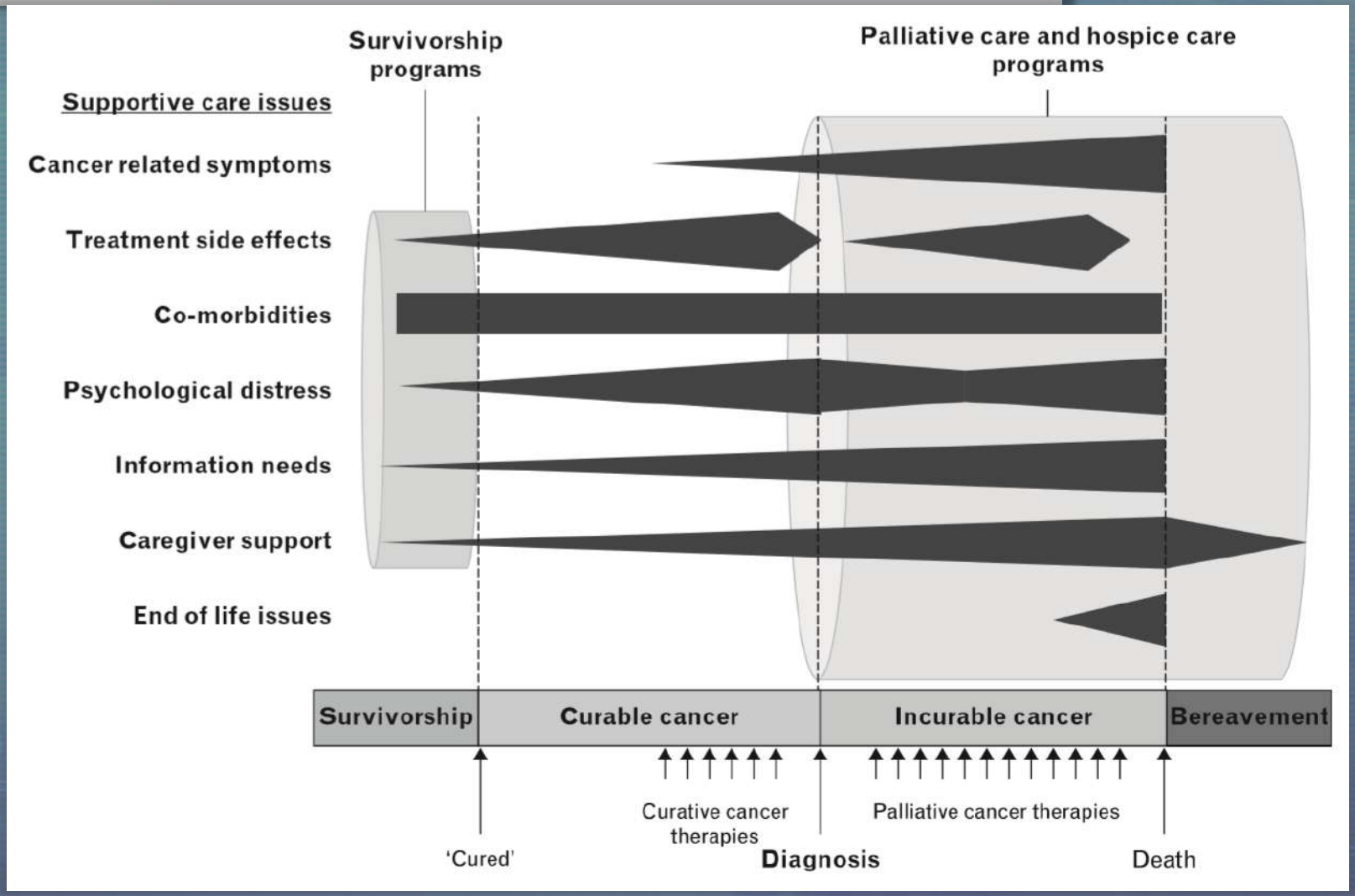
Curr Opin Oncol 2014



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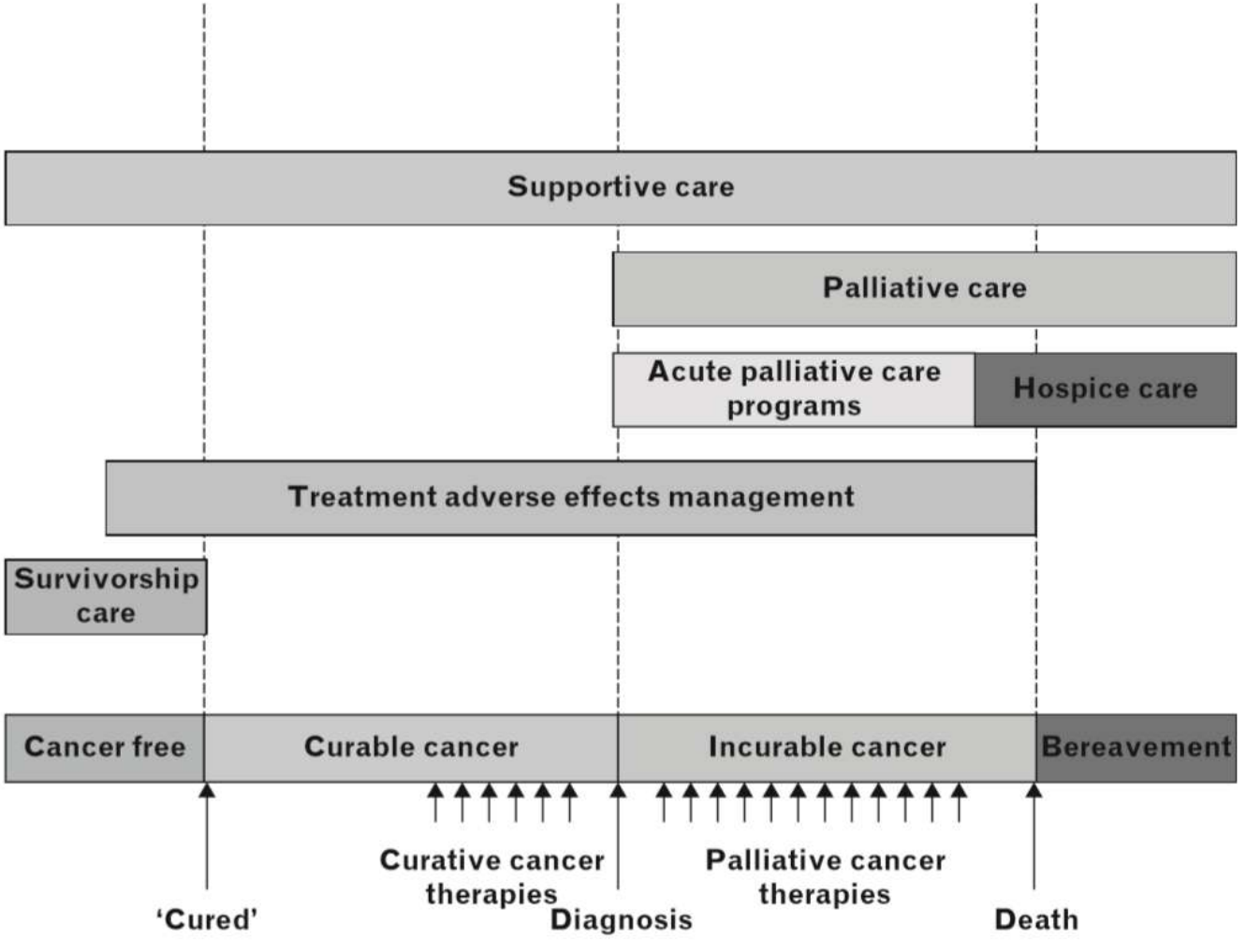
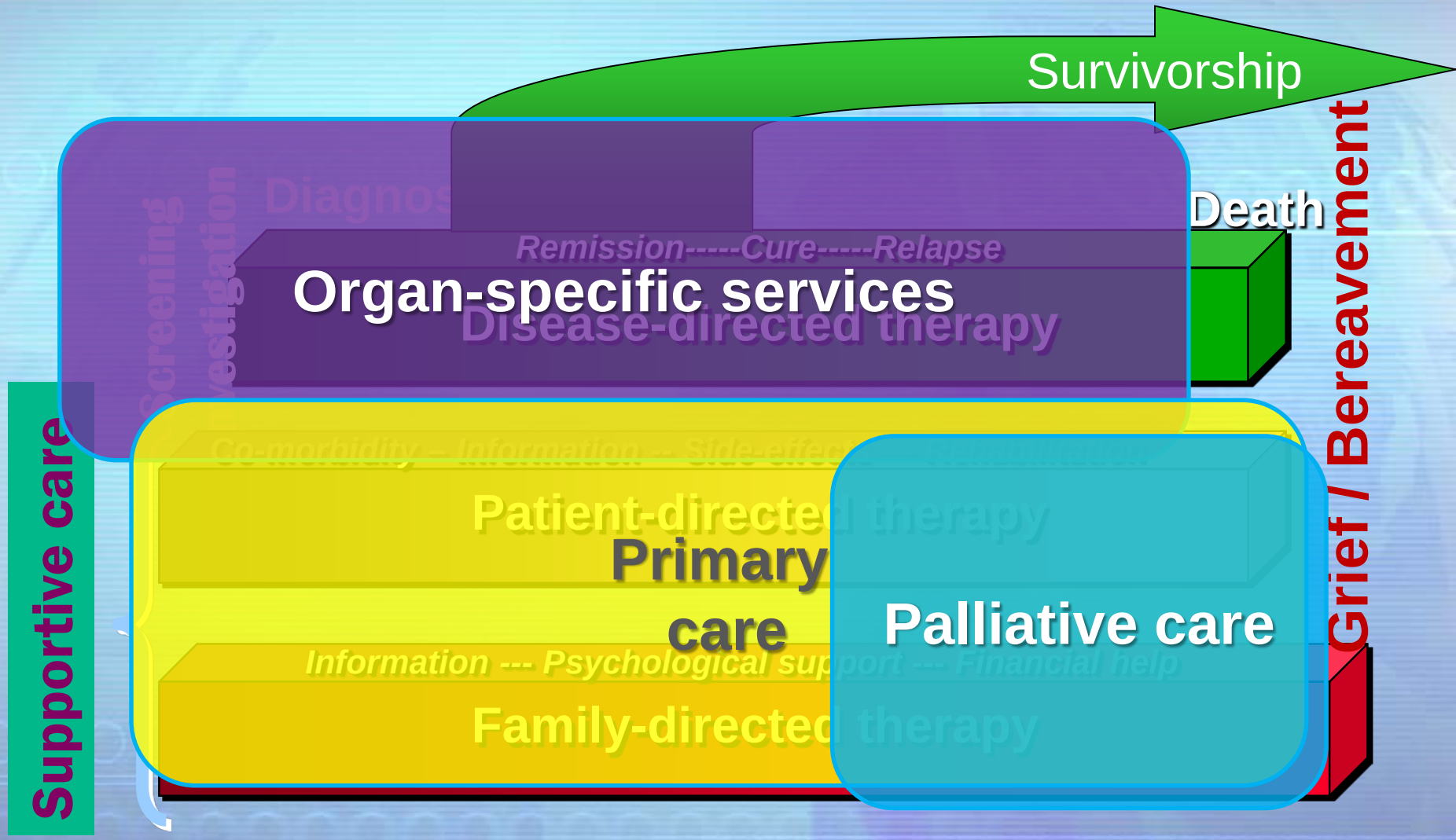


Sheffield model of supportive care

Who does what and when?



Adapted from: Ahmedzai, Walsh *Seminars in Oncol* 2000

And now – ‘ESC’


NHS
England
ENHANCED
SUPPORTIVE CARE
Integrating supportive care in oncology
(Phase I: Treatment with palliative intent)

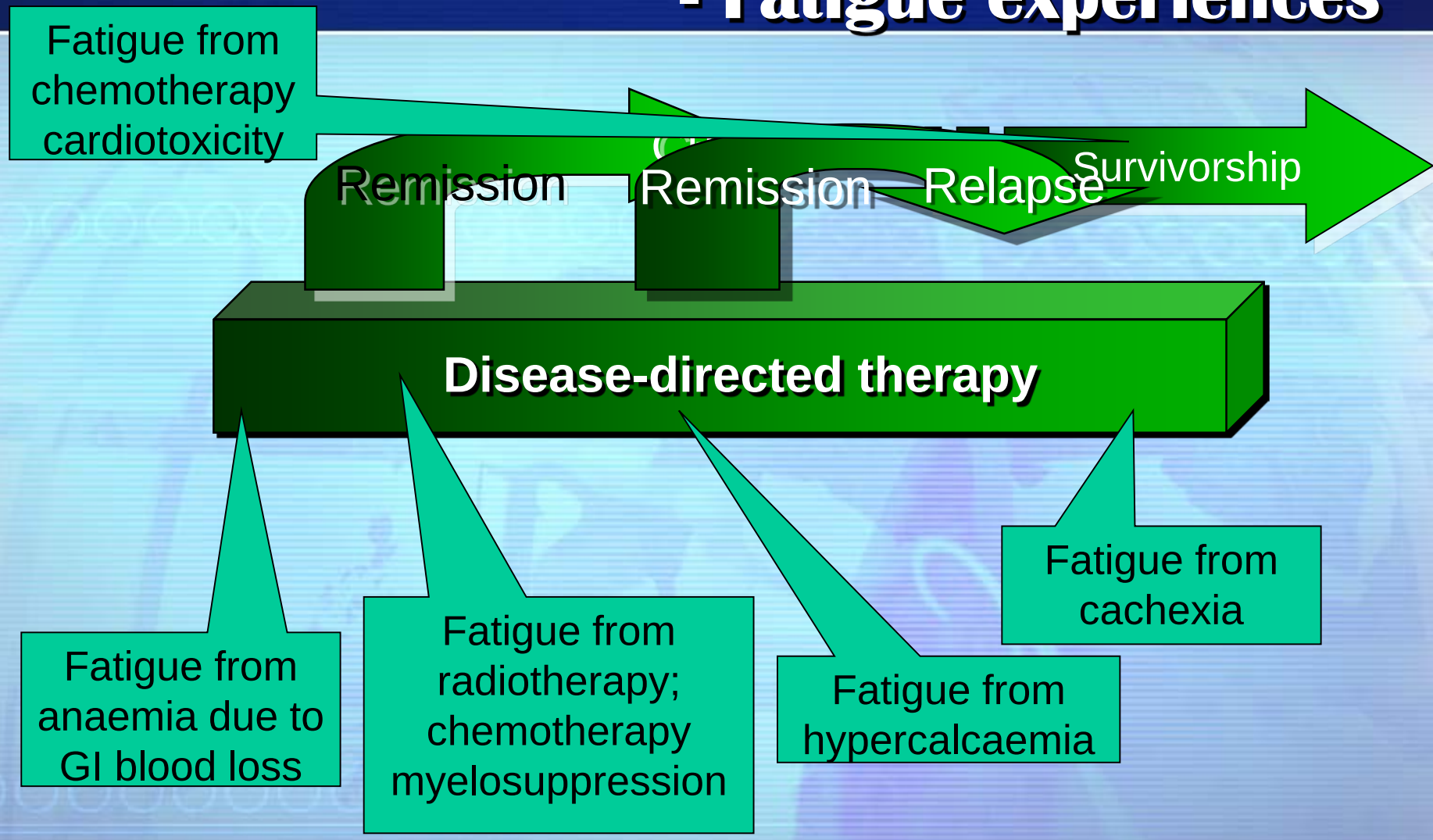
Who needs supportive care?

- Patients and families seeking information about the illness and treatments
- Patients and carers with psychosocial distress
- Patients with unrelieved symptoms or controlled symptoms with unacceptable toxicity
- Patients and carers who are struggling with changing aims of anti-cancer treatment
- Patients and families approaching the end of life

Symptoms and side-effects

Symptoms of cancer	Side-effects of cancer treatment
Fatigue and weakness	Fatigue and weakness
Pain	Pain
Appetite, nausea and bowel problems	Appetite, nausea and bowel problems
Breathing problems	Breathing problems
Sexuality and intimacy issues	Sexuality and intimacy issues
Problems with body image	Problems with body image

Sheffield model of supportive care - Fatigue experiences



Adapted from: Ahmedzai, Walsh *Seminars in Oncol* 2000

Adverse events of targeted therapies

Jean A. Klastersky *Curr Opin Oncol* 2014

Table 1. Main adverse reactions – % all severity grades and ( ) grades at least 3 and 4

	Systemic manifestations			Renovascular			Skin and mucosa			Gastrointestinal symptoms			
Targeted therapy	Fatigue/ asthenia	Arthralgia/ myalgia	Headache	Hypertension	Proteinuria	↑ Creatinine	Rash and similar	Hand and foot syndrome	Stomatitis/ mucositis	Anorexia	Nausea/ dyspepsia	Vomiting	Diarrhea
Bevacizumab	20 (4)		22 (3)	36 (8)	5 (0)		10 (3)	(3)			6 (0)		5 (2)
Sorafenib	28 (4)	15 (3)	7 (0)	30 (12)	8 (1)		31 (4)	51 (17)	12 (1)	26 (2)	19 (1)	13 (0)	52 (8)
Axitinib	37 (10)	19 (2)	11 (1)	42 (17)	13 (3)		13 (1)	28 (6)	15 (1)	31 (4)	30 (2)	18 (1)	13 (1)
Sunitinib	63 (19)	28 (2)	22 (1)	41 (15)	14 (4)	46 (1)	23 (1)	50 (11)	27 (1)	37 (3)	46 (2)	27 (3)	57 (8)
Pazopanib	55 (11)	30 (3)	23 (3)	46 (16)	18 (4)	32 (1)	18 (1)	29 (6)	14 (1)	37 (1)	45 (2)	28 (2)	63 (9)
Aflibercept	67 (7)	32 (1)	42 (7)	51 (13)	48 (11)					21 (0)	12 (0)	2 (0)	11 (0)
Tivozanib	29 (3)			45 (11)	64 (3)	70 (1)							33 (2)
Cabozantinib	63 (16)			22 (12)				30 (8)	19 (1)	54 (6)	49 (5)	28 (4)	51 (3)
Regorafenib	28 (4)			30 (1)				40 (19)	36 (2)	26 (2)			32 (8)
Vandetanib	24 (6)		26 (0)	32 (9)			45 (4)		56 (8)	26 (1)	29 (1)	14 (1)	30 (2)
Cetuximab	9 (0)	(7)	(7)				18 (12)	7 (0)	6 (0)	5 (0)	6 (0)	6 (0)	30 (0)
Panitumumab	24 (4)						64 (5)	20 (1)		22 (3)	22 (1)	18 (2)	21 (1)
Trastuzumab		(8)	(4)	14 (1)									(6)
Pertuzumab	12 (1)		5 (0)				19 (0)			2 (0)	19 (0)	7 (1)	24 (7)
Lapatinib	19 (0)		9 (0)				29 ()		2 (0)	10 (1)	28 (0)	18 (0)	48 (7)
Gefitinib	30 (6)						62 (32)	4 (4)	3 (1)	8 (3)	7 (1)		36 (15)
Erlotinib	60 (30)						94 (65)	11 (9)	17 (3)	37 (11)	14 (7)		17 (14)
Crizotinib	27 (2)						9 (0)	8 (0)			55 (1)	47 (1)	60 (0)
Olaparib	48 (6)	12 (0)	18 (0)							18 (0)	68 (2)	31 (2)	23 (2)
Imatinib	35 (1)						31 (0)			32 (0)	28 (1)	16 (3)	31 (4)
Vemurafenib	11 (2)		4 (1)				10 (8)				7 (1)	3 (1)	5 (1)
Vismodegib	36 (4)	68 (4)								23 (3)	29 (11)		22 (1)
Everolimus	33 (3)	20 (2)	19 (1)				36 (1)		56 (8)	29 (1)	29 (1)	14 (1)	30 (2)
Ipilimumab		37 (0)					25 (1)						36 (4)
Lambrolizumab	30 (1)	19 (0)	14 (0)			2 (1)	21 (2)			4 (1)			

Pain in cancer – *multiple causes*

Acute and chronic pain management in palliative care

Best Practice & Research Clinical Obstetrics & Gynaecology
Vol. 15, No. 2, pp. 203–234, 2001

Vitaly Gordin MD

Table 2. Tumour-related and therapy-related pain syndromes.

Tumour-related pain syndromes	Cancer therapy-related pain syndromes
Bone pain	Postchemotherapy pa
bone pain	Chronic painful pe
ses	Avascular necrosis
	Plexopathy associat
	infusion
Atlantoaxial destruction and odontoid fractures	Chronic pain associated with hormonal therapy
C7 to T11 syndrome	Gynaecomastia with hormonal therapy for prostate cancer
T12 to L1 syndrome	Chronic postsurgical pain syndromes
Sacral syndrome	Postmastectom
Back pain and epidural compression	Post-radical ne
and hip	Post-thoracoto
	Postoperative f
Leptomeningeal metastases	Phantom pain syndromes
Base of skull metastases	Stump pain
Painful cranial neuralgias	Postsurgical pelvic floor myalgia
Tumour involvement of the peripheral nervous system	Chronic postradiation pain syndromes
	Plexopathies
Tumour-related radiculopathy	Chronic radiation myelopathy
	Chronic radiatio
	Burning perineu
	Osteoradionecro
Tumour-related mononeuropathy	
Paraneoplastic painful peripheral neuropathy	
Pain syndromes of the viscera and miscellaneous tumour-related syndromes	
Heaptic distention syndrome	
roperitoneal syndrome	
estinal obstruction	
arcinomatosis	
erineal pain	
Ureteric obstruction	
Paraneoplastic nociceptive pain syndrome	
Tumour-related gynaecomastia	

Bone cancer

Chemotherapy

Head and neck

Post-surgical

Neural plexopathies

Radiation

Visceral

Pains in cancer arise from the disease – *and the treatment*

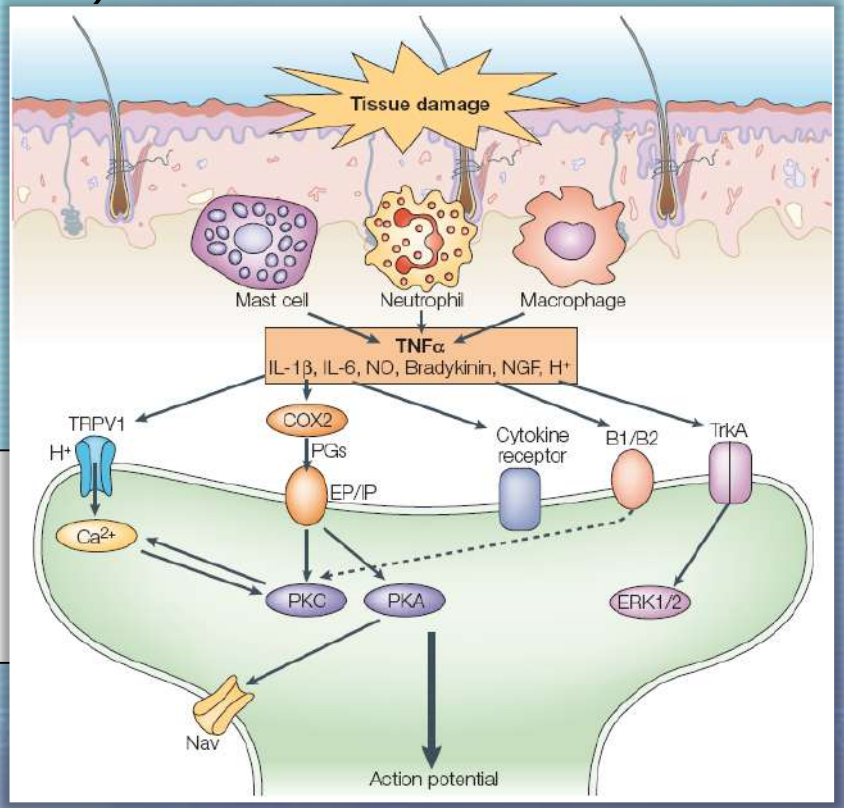
ALL - mucositis with intensive chemotherapy – Days 5 - 40

Why is mucositis painful?

- Destruction of protective role of epithelium
- Exposure and sensitisation of nerve endings to H^+, local and circulating noxious agents
- Induction of painful sensory signals and transmission to brain (via cranial or peripheral nerves and spinal cord)

ROLE OF THE IMMUNE SYSTEM IN CHRONIC PAIN *Neuroscience* 2005

Fabien Marchand, Mauro Perretti‡ and Stephen B. McMahon**



Multiple myeloma – HSCT – Day 10

Chronic graft-versus-host disease in patient ‘cured’ of myeloma

Chemotherapy-induced neuropathic pain

"I get sharp electric shocks that shoot up my legs"

"When I walk it feels as I have sharp stones in my shoes"

"My feet feel like they're burning / blocks of ice"

Chronic symptoms in multiple myeloma survivors

Living With Advanced But Stable Multiple Myeloma: A Study of the Symptom Burden and Cumulative Effects of Disease and Intensive (Hematopoietic Stem Cell Transplant Based) Treatment on Health-Related Quality of Life

JPSM 2013

Elaine Boland, MD, MRCP, Christine Eiser, PhD, Yousef Ezaydi, MRCP, Diana M. Greenfield, PhD, Sam H. Ahmedzai, FRCP, and John A. Snowden, MD
Academic Unit of Supportive Care (E.B., S.H.A.) and; Academic Unit of Psychology (C.E.), University of Sheffield; Department of Haematology (Y.E., J.A.S.), Sheffield Teaching Hospital NHS Foundation Trust; Weston Park Hospital (D.M.G.), Sheffield Teaching Hospital NHS Foundation Trust; and Late Effects Group Sheffield (D.M.G., J.A.S.), Sheffield, United Kingdom

Late effects in myeloma survivors

Dimensions of survivorship in this study –

- Physical symptoms and quality of life
- Endocrine abnormalities
- Cardiac dysfunction
- Sexual problems

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Late effects in myeloma survivors
Pain experience

	Males	Females	P-value
Worst pain	4.8 (1.3)	3.5 (2.0)	0.15
Least pain	1.6 (1.8)	1.6 (1.3)	0.98
Average pain	3.9 (2.4)	3.0 (2.0)	0.28
Pain right now	3.0 (2.8)	2.5 (1.8)	0.53
Pain Interference	3.0 (2.6)	3.0 (2.3)	0.97

Table 3: BPI-SF Mean (SD) for males and females (Pain range 0 -10)

- 67% of patients had sensory neuropathy
- 50% had evidence of neuropathic pain

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Late effects in myeloma survivors

Pain experience

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JPSM 2013

Elaine Boland, MD, MRCP, Christine Eiser, PhD, Yousef Ezaydi, MRCP,

Table 2

Quality of Life From the EORTC QLQ-C30

Components	Median (IQR)	Mean (SD)
Functional scales		
Physical functioning	60 (41.7–80.0)	60.6 (25.4)
Role functioning	67 (33.0–79.0)	55.2 (31.2)
Emotional functioning	71 (44.0–92.0)	68.8 (23.9)
Cognitive functioning	83 (50.0–95.7)	71.8 (25.9)
Social functioning	50 (33.0–67.0)	46.9 (28.3)
QoL/global health status		
QoL/global health status	57.5 (50.0–67.0)	58.8 (17.4)
Symptom scales/items		
Pain	33 (17.0–67.0)	45.6 (31.9)
Fatigue	44 (33.0–67.0)	48.9 (29.0)
Insomnia	33 (0–67.0)	35.4 (36.5)
Appetite loss	33 (0–33.0)	27.0 (31.0)
Dyspnea	33 (0–67.0)	33.3 (30.6)
Nausea and vomiting	0 (0–17.0)	11.1 (17.3)
Constipation	0 (0–33)	14.4 (24.2)
Diarrhea	0 (0–25)	10.4 (19.7)

Table 4

Correlations of Serum Cytokines With EORTC QLQ-C30 Components

Components	IL-6 (*P*-value; *r*)	TNF-α (*P*-value; *r*)
Functional scales		
Physical functioning	*0.03*; *−0.38*	0.62; −0.09
Role functioning	0.07; −0.33	0.63; 0.09
Emotional functioning	0.85; 0.03	0.93; −0.02
Cognitive functioning	0.61; −0.09	0.39; 0.16
Social functioning	0.81; −0.04	0.22; 0.22
QoL/global health status		
QoL/global health status	0.23; −0.22	0.63; −0.09
Symptom scales/items		
Pain	*0.02*; *0.41*	0.84; 0.04
Fatigue	0.37; 0.16	0.89; 0.25
Insomnia	*0.02*; *0.40*	0.47; 0.13
Appetite loss	*0.02*; *0.41*	0.09; 0.30
Dyspnea	0.20; 0.23	0.66; 0.08
Nausea and vomiting	0.28; 0.20	0.31; 0.18
Constipation	0.57; 0.34	0.16; 0.26
Diarrhea	0.37; −0.16	0.51; −0.12

Table 5

Correlations of Serum Cytokines With BPI-SF Components

BPI-SF	IL-6 (*P*-value; *r*)	TNF-α (*P*-value; *r*)
Average pain	*0.03*; *0.38*	0.15; 0.27
Pain interference	*0.003*; *0.52*	0.46; 0.14

Chronic inflammatory mediators – especially IL-6 – are important factors in pain, depression and appetite suppression

Genetic predisposition to chronic pain in myeloma survivors

Patient-Reported Outcomes (PRO) in the Setting of Relapsed Myeloma: The Influence of Treatment Strategies and Genetic Variants Predict Quality of Life and Pain Experience.

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Cathy D Williams[4*], Anna Hockaday[5*], Jamie Cavenagh[6], Christopher Parrish, MD[7*], Kwee L Yong, MBChB, PhD[8*], Jim Cavet[9*], Hannah Hunter[10], Jennif
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Plymouth, United Kingdom; [11]University Hospitals Bristol NHS Foundation Trust, Bristol, United Kingdom; [12]Dept. of Haematology, Pinderfields Hospital, Wakefield, United Kingdom; [13]University of Leeds, Cli
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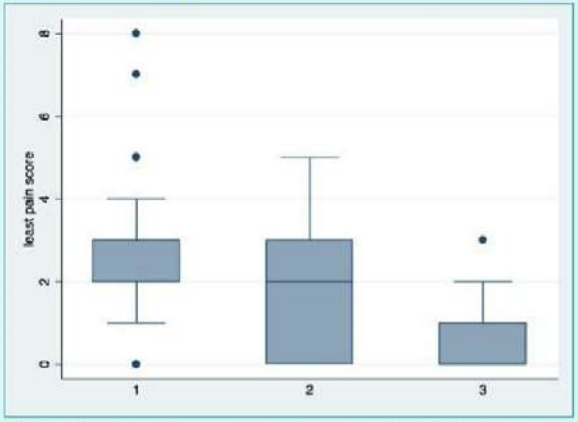
Ahmedzai et al, poster at *Amer Soc Hematol* 2015

Figure: Pain and genotypes at rs13361160



BPI least pain score at end of PAD treatment according to genotype at rs13361160 in the intergenic region between CCT5 and FAM173B genes on chromosome 5p15.2. Regression analysis adjusted for treatment group, age at randomisation and gender, p=0.003, n=48. Genotype groups as follows: 1=TT, 2=TC, 3=CC

Initially increased pain after salvage stem cell transplant compared to conservative management –

- But by 2 years, transplant patients had lower pain

Pain was associated with several genetic variations –

- OPRD1 (delta opioid receptor)
- ABCB1 (drug transporter)
- SNP rs13361160 in the chaperonin CCT5 gene (generalised pain)

Principles of pain management in long-term cancer survivors

- Cancer survivors are trying to return to normal daily life
  - Prefer not to keep coming back to hospital
  - Prefer not to be drugged up
  - Want to carry on driving
  - Want to return to work and hobbies

Sheffield implementation of supportive care in haematology

- Supportive and palliative care team visits Haematology in-patient wards and day wards almost every day – often >1/day
- Consultant/trainee doctors available every day – including overnight and at weekends
- Since 2015 – clinical nurse specialist working Saturday and Sunday 09.00 – 17.00
- Joint guidelines from supportive care and haematology departments

UK Myeloma supportive care guidelines (Snowden et al, *Brit J Haematol* 2011)

bjh guideline

Guidelines for supportive care in multiple myeloma 2011

John A. Snowden,[1] Sam H. Ahmedzai,[2] John Ashcroft,[3] Shirley D'Sa,[4] Timothy Littlewood,[5] Eric Low,[6] Helen Lucraft,[7] Rhona Maclean,[1] Sylvia Feyler,[8] Guy Pratt[9] and Jennifer M. Bird[10] On behalf of the Haemato-oncology Task Force of the British Committee for Standards in Haematology and UK Myeloma Forum

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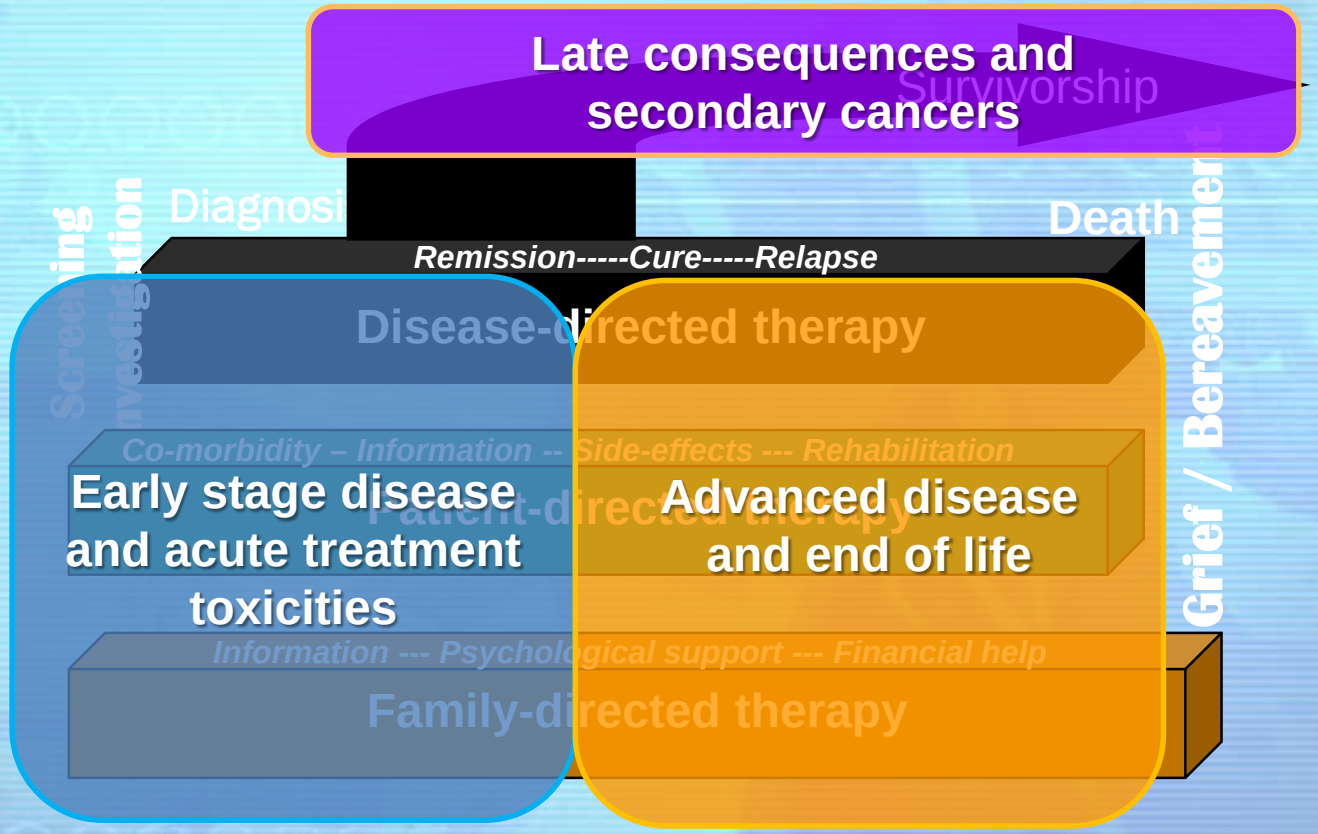
NCRI Supportive and Palliative Care CSG – New research subgroups 2016



What about outside cancer?

Supportive care model also works well for

- Sickle cell disease
- Haemophilia

- Rheumatology and auto-immune diseases (in future – role for stem cell transplant?)

- And of course – lung, cardiac, renal, neurology…

The big question

Not all patients with cancer or chronic disease need intensive supportive or palliative care

So - how do we know what patients' and families' needs are?

Answer – Holistic needs assessment!

In conclusion….

- Palliative care and supportive care NOT the same
- Supportive care is NOT ‘early palliative care’
- Supportive care is based on needs, not stage of disease – offered at all stages, including ‘survivors’
- Supportive care works best alongside disease-modifying therapies – mainly acute sector
- Some palliative care specialists can contribute to supportive care, especially in oncology – but needs a new dedicated workforce
- Future challenge – ‘supportive care for all’?

Accompanying the patient
- on the whole journey – to recovery or death