

# National Cancer Survivorship Initiative

## ***Haematology Survivorship***

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Improvement*

### **NCSI**

#### **CANCER & SURVIVORSHIP**

#### **CARE PLANNING & INFORMATION**

#### **PATHWAYS – the survivorship model**

#### **END OF LIFE CARE**

#### **LANGUAGE & TERMINOLOGY**

## *The cancer “story” has changed..*

- *Use the word & more honest with patients –*
  -
- *Improved & new chemotherapy*
- *Better side effect management*
  - *Better radiation therapy*
- *Speedier access to diagnosis*
- *Increased specialist expertise*
- *Palliative Care services & support*
- *Improved survival duration*

*BUT.....*

### **WEAK PUBLIC & “PURCHASER” UNDERSTANDING**

*“CURED” of cancer  
done in secondary care - i.e.  
“the hospital”*

*“DYING” of cancer  
Palliative care = terminal  
care*

***Don’t really understand  
“living with cancer”***

# N.C.S.I.

- The evidence suggests that current *follow up arrangements are not meeting the medical, psychological, social, spiritual, financial and information needs* that cancer survivors may have following their treatment.
- *Routine follow up appointments are not effective in terms of detection of recurrence.* In practice, the large majority of recurrences are detected either by patients themselves or on investigations which can be planned without a patient having to attend a clinic.

**25% unmet needs a year after treatment Ames et al 2009, JCO**

# N.C.S.I. Vision

- a **cultural shift** in the approach to care and support - a greater focus on recovery, health and well-being
- a shift towards **holistic assessment, information provision** and personalised care planning.
- a shift towards **support for self-management**, supported by the appropriate clinical assessment, support and treatment.
- a shift to **tailored support** for consequences of treatment, signs and symptoms of further disease and for those with advanced disease.
- a shift to a new emphasis on measuring experience and outcomes

## Who are the two million cancer survivors?

Sex / Age / Site	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60
0-17	16,000	0.8
18-64	774,000	38.7
Colorectal	250,000	12.5
Lung	65,000	3.2
Breast	550,000	27.5
Prostate	215,000	10.7
Other	920,000	46



**2 million cancer survivors living with  
and beyond cancer in UK - 1.6 m  
completed therapy  
Prevalence increases by 3.2% p.a.  
4 million in 20 years**

**Haematology prevalence <100,000  
currently**

**Require a viable strategy for -**

- **Follow-up & support**
- **Detection and management of progression and/or recurrence**
  - **2nd malignancy**
  - **Diagnose end of life phase**
  - **Late complications -**
    - *Physical*
    - *Psychological*
    - *social*

## ***Chronic cancer – patient story; F dob 1944***

- 10/1996 – back pain Myeloma
- 11/1996 – 05/1997 - chemotherapy, analgesia, peripheral blood autologous stem cell transplant
- (“professional cancer patient”)
- 09/1997 – back to work; teaching; Fentanyl patches
- retiral c 2002
- 12/2004 – sternal & spinal lesions
- 01/2005 – local irradiation, chemotherapy – ongoing to 09/2005
- 05/2005 – rib irradiation
- 06/2006 – balloon kyphoplasty L4
- 07/2007 – 03/2008 – chemotherapy, Bortezomib
- 03/2010 – progression, starting chemotherapy, Lenalidomide
- 08/10 – Lenalidomide resistant, further Bortezomib

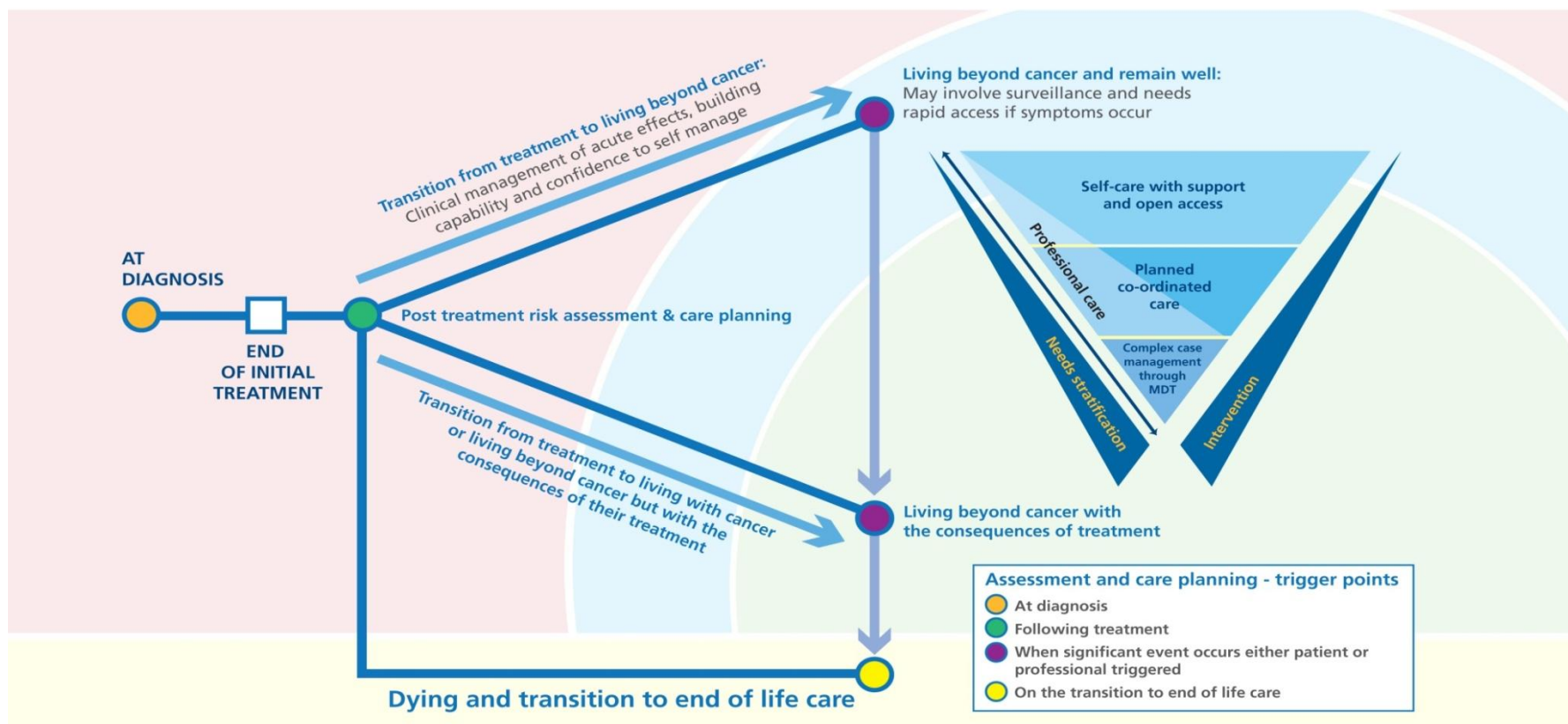
***>15 year survival from diagnosis likely***

# ***SURVIVORSHIP - care planning, risk stratification.....***

- ***Clear post-treatment assessment & care planning - sets context for both patient & primary care; also at key points e.g. relapse – who, why, where, when, what & how etc***
- ***Define the context – e.g. persistent disease or remission and/or ongoing treatment (e.g. haematology, urology)***
- ***Identify patients appropriate for self-management – patient & cancer “risks” – develop pathways***
- ***Access to appropriate symptom management – e.g. dyspnoea***
- ***Post-treatment/cancer effects surveillance & management – e.g. urology, lower g-i, gynae etc)***
- ***Some problems are not unique to cancer***
- ***Discussion/identification of transition to end-of-life care - all cancers***
- ***Communication with GP computer systems – co-ordinate cancer reviews***



# Survivorship & cancer - pathways



Characteristics may include:

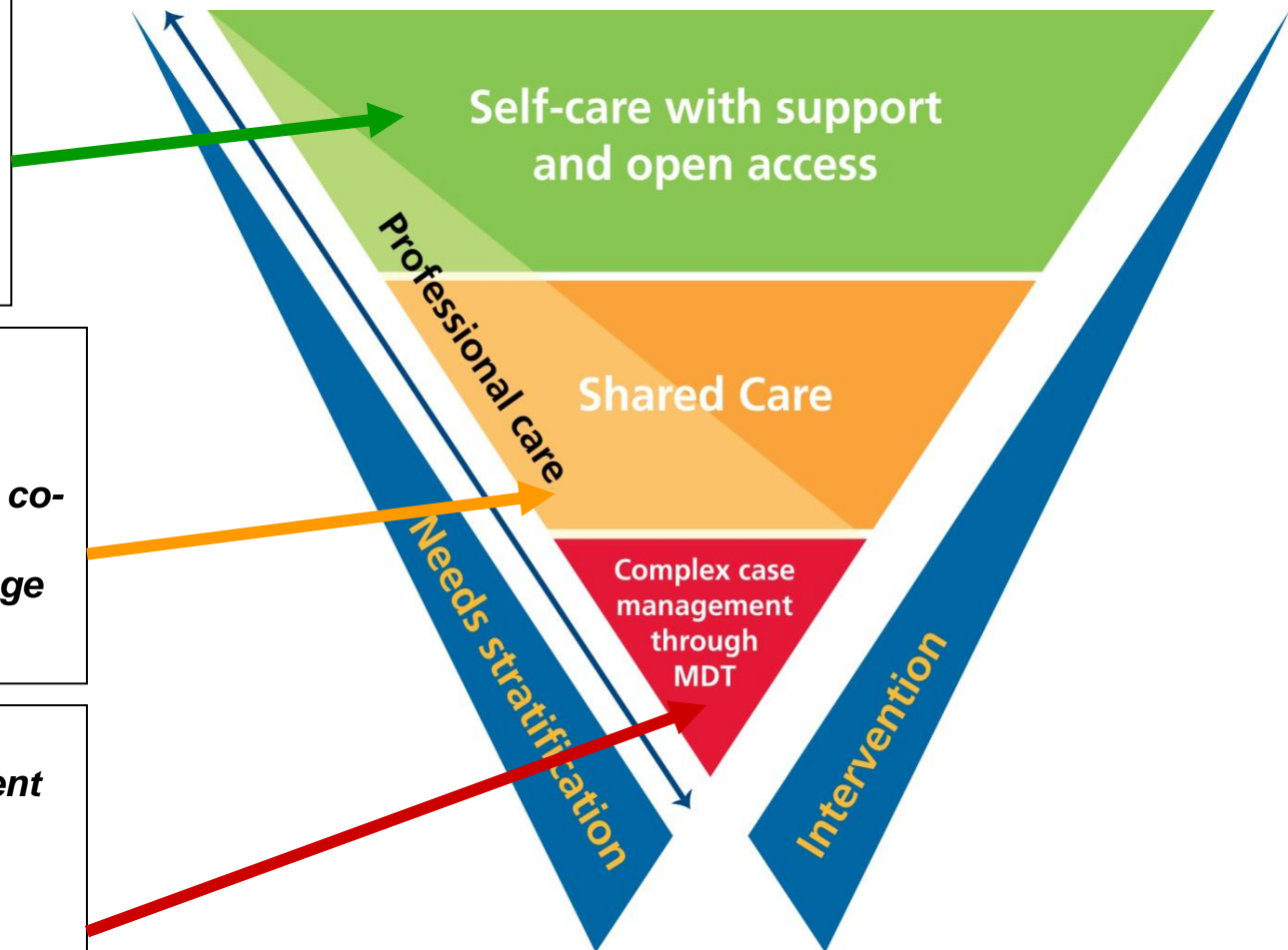
- **Stable disease pattern**
- **Clinical and holistic assessment & care plan agreed**
- **Continued surveillance tests**
- **Ability to re access specialist team**

Characteristics may include:

- **Clinical examination required**
- **Clinical or individual “risks” (disease, treatment, person) e.g. co-morbidity**
- **Those who decline to self manage**

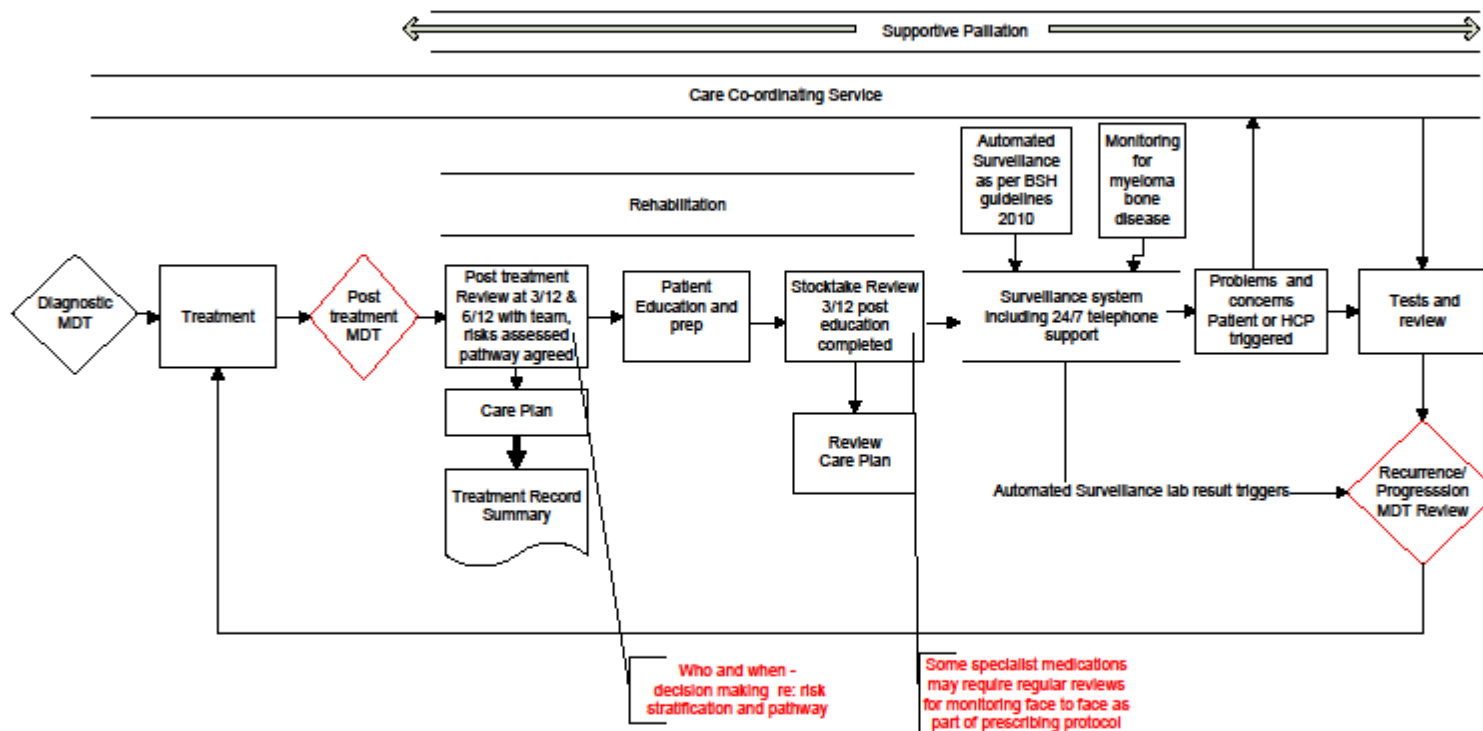
Characteristics may include:

- **Rare tumours/ Complex treatment regimens**
- **Input from other clinical teams required**
- **Exacerbations of disease/recurrence of symptoms**
- **Transition/classification to end of life care**

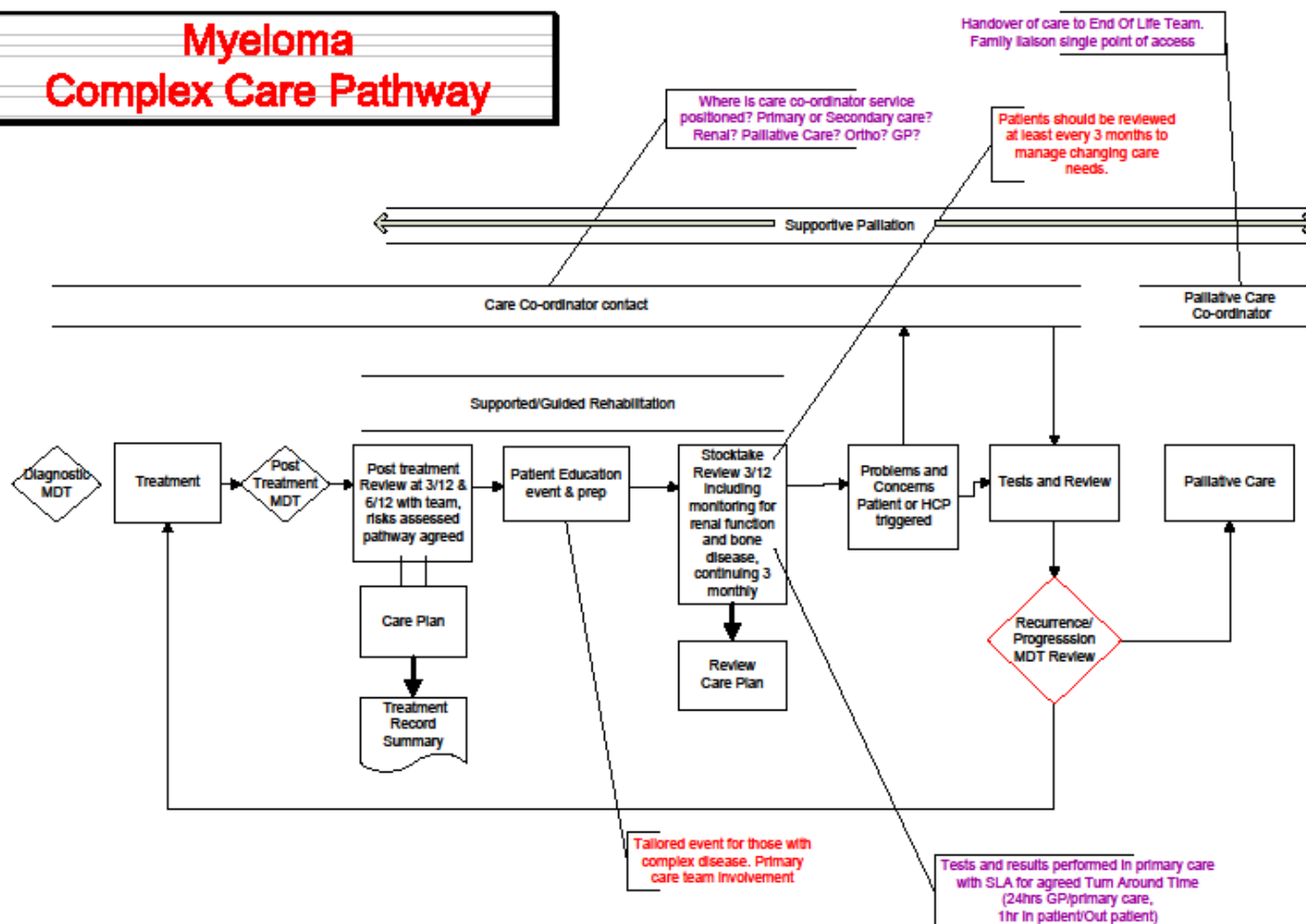


**Potential care model being tested**

# Myeloma Supported Self Management Pathway



# Myeloma Complex Care Pathway



## MYELOMA PATIENTS – Infoday 04/2010

- ***“Bonded” to secondary care - feeling of confidence in its competence***
- ***GP doesn’t know anything about the condition***
- ***No written care plan***
- ***Problem with blood test surveillance – samples, tests, geography etc***
- ***When well - many would be happy with test & call – if the system were reliable/made it possible***
- ***No sense of control over their plan of care and whether it meets their needs***
- ***Meeting “friends” at the hospital – i.e. fellow survivors***

## ***“Chronic” Haematology conditions - observations/experience***

- *HMDS Leeds postal monitoring low -grade conditions through blood testing*
- *Nurse-led & other telephone clinics*
- *Sickle cell anaemia – education & self-management*
- *Haemophilic disorders*

# Colorectal concepts

- **Green** – early cancer/curative procedure
- **Amber** – recurrence risk – yrs 1&2 - active monitoring
- **Red** – complex
- **Blue** – too frail for active treatment of recurrence
- Anal vs Colon cancer – effects, survivorship requirements
- Stoma care/closure etc
- Diet advice, healthy living

***Defining needs of identifiable clinical risks/problems***

# TECHNOLOGY

TELEPHONE

Text messages

E-mail

On line support Palm pilot

i-phones etc

**Alternatives to the  
traditional appointment**

Internet survivorship web  
sites - **ONCOLINK**





## ***Survivorship - principles for practice:***

- ***Risk stratified care based on disease, treatment and the person***
- ***A shift to supported self-management with rapid re-access***
- ***Individualised care plan for all patients***
- ***Improved information that empowers and offers choice***
- ***Realistic/evidence-based/cost-effective 'models of care'***

## **REVISED NHS PLAN 2010**

- ✓ ***Preventing people from dying prematurely***
- ✓ ***Enhancing quality of life for people with long-term conditions***
- ✓ ***Helping people to recover from episodes of ill health or following injury***
- ✓ ***Ensuring people have a positive experience of care***
- ✓ ***Treating and caring for people in a safe environment and protecting them from avoidable harm***

**Secondary care**

**Patient**

**Primary care**



**Safety  
Quality  
Outcome**



***Responsibility in cancer is  
dynamic & a partnership with  
Clinicians in primary &  
secondary (& tertiary)care***

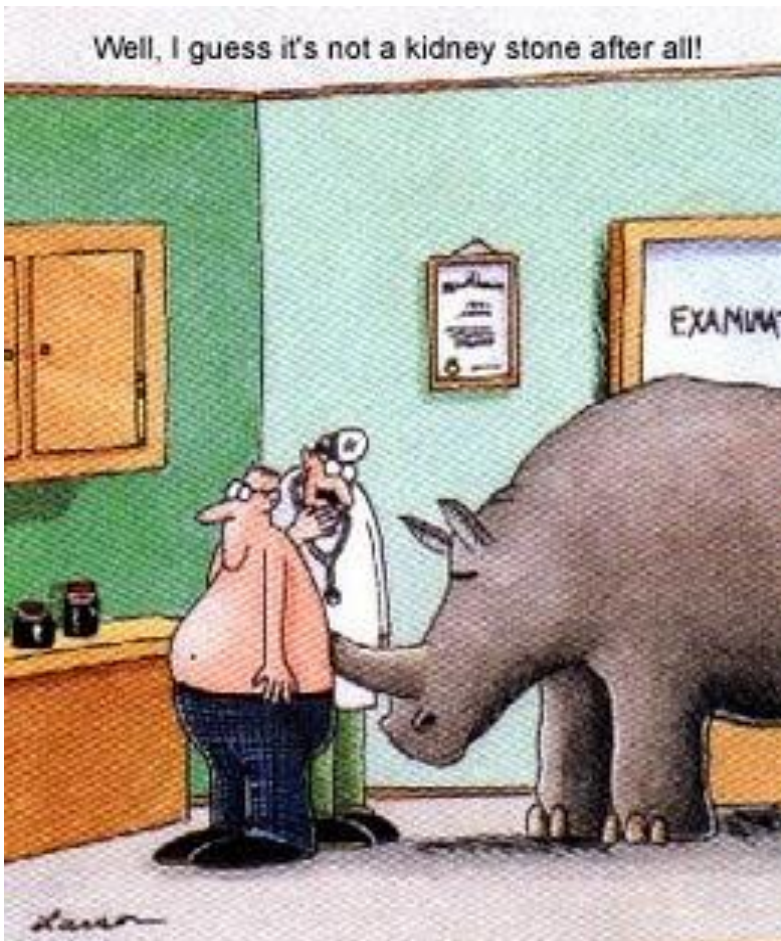


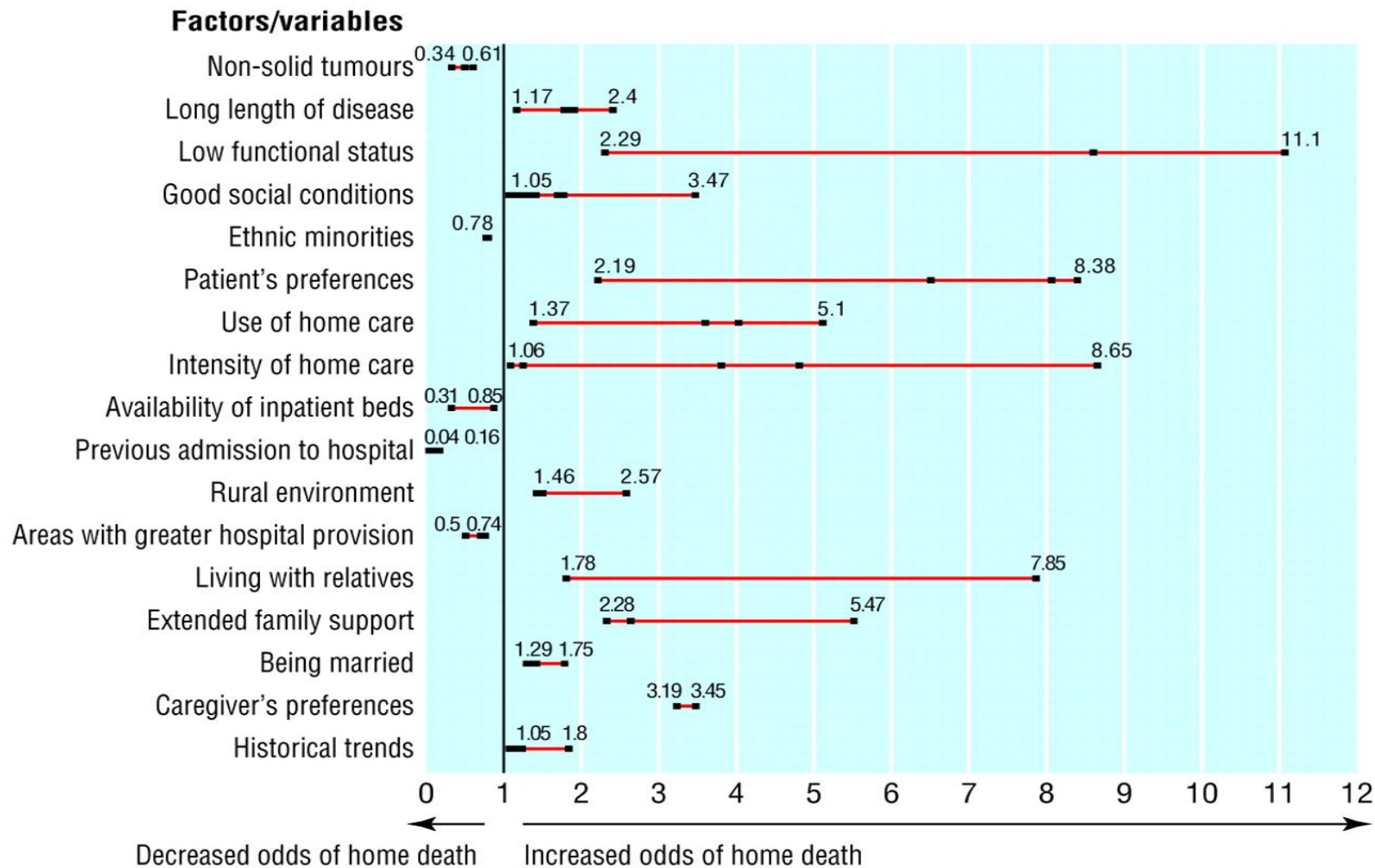
## ***“END OF LIFE” CARE***

*Patients with disease not amenable to effective curative or life-prolonging interventions*

*Important to talk about it and have it as a key part of post–treatment care planning when appropriate*

*NEJM study on early Palliative Care involvement/intervention of benefit in lung cancer (Temel et al , NEJM 363, 733 – 742 (2010))*





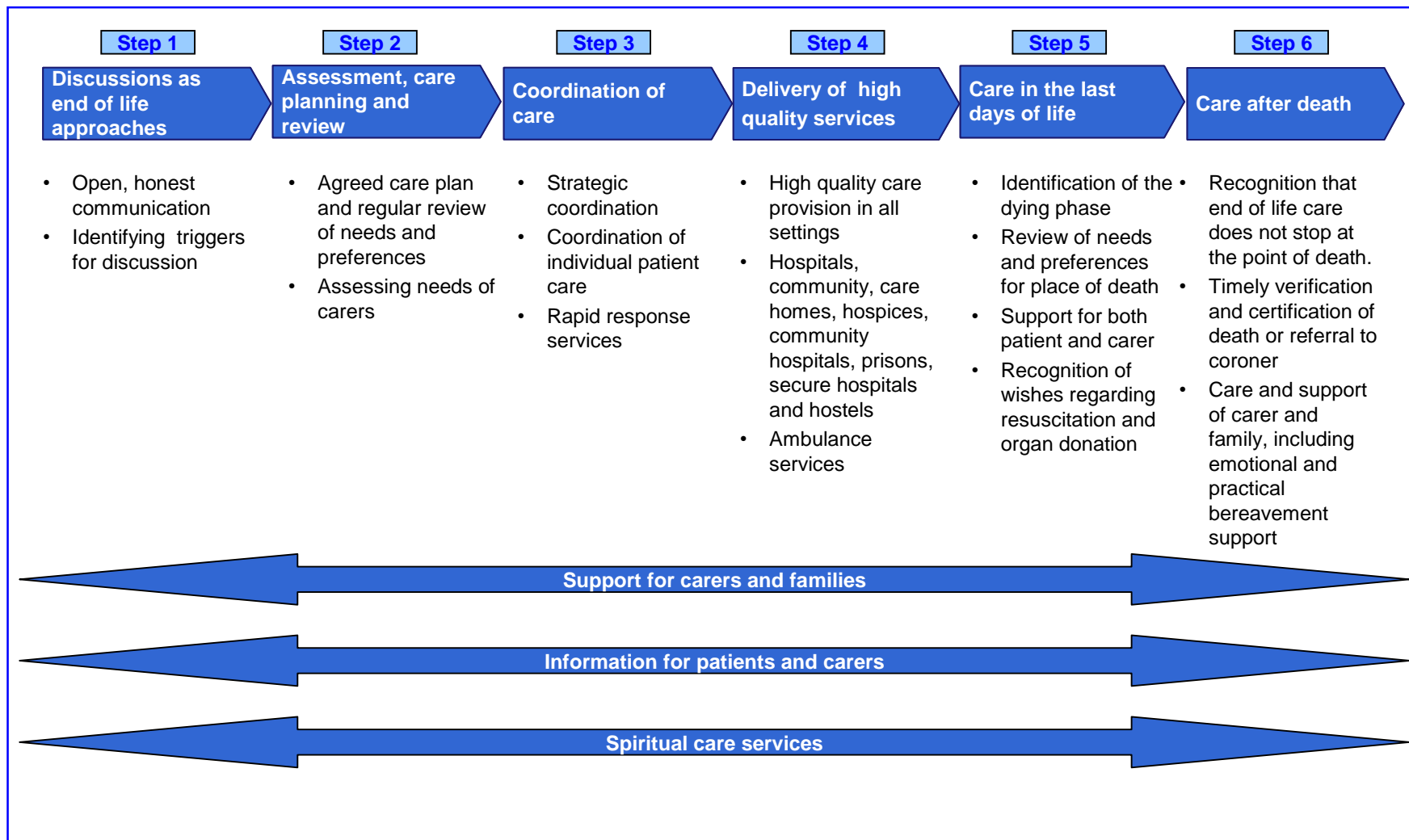
*Odds ratio for dying at home*

# The End of Life Care Strategy: Rationale

- ***There is a major mismatch between people's preferences for where they should die and their actual place of death***
  - *Most would probably like to die at home*
  - *Only around 18% do so with a further 17% in care homes*
  - *Acute hospitals accounting for 58% of all deaths*
  - *Around 4% in hospices*
- ***Only around one third of general public have discussed death and dying with anyone***
- ***Problems***
  - *As a society we do not talk about death and dying – this contributes to its low profile in health and social care*
  - *Most people do not discuss their own preferences for end of life care with their partner / family, hampering individual planning*
- ***Actions***
  - *A national coalition on end of life care will be established, led by the National Council for Palliative Care with funding from DH*
  - *A tool to assess change in awareness / attitudes will be developed*
  - *Local end of life care plans to include actions on awareness / attitudes*

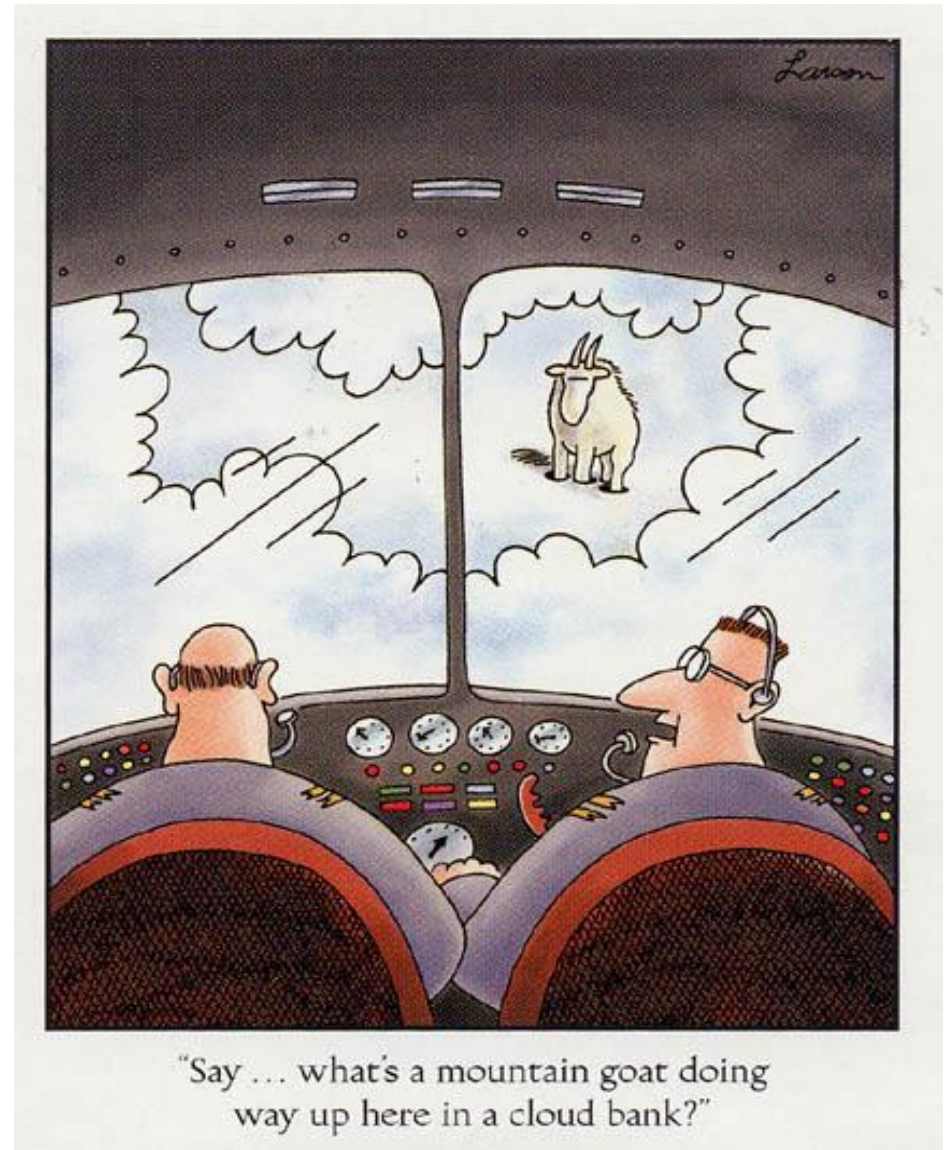


# The End of Life Care Pathway.....



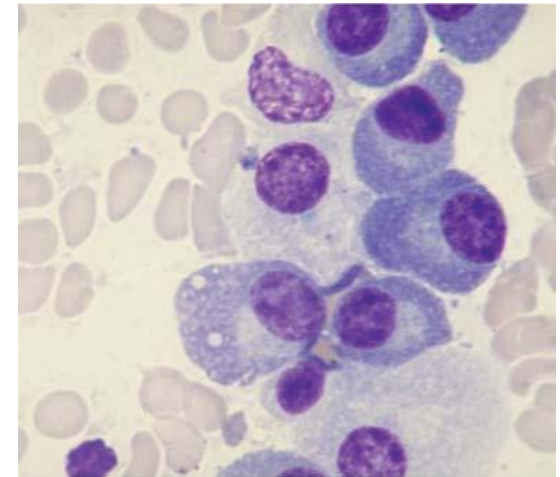
## **GSF is about .....**

- ***Accepting the clinical situation***
- ***Planning ahead & setting the context for :***
  - ***The patient***
  - ***The family***
  - ***THE MEDICAL TEAM***
  - ***PRIMARY CARE***
- ***And recognising reality and practicality***



## **GSF – in practice**

- **69 yrs old female; myeloma diagnosed 09/2006, complications at presentation , CTD chemotherapy, fracture pinning, R-T etc – plateau achieved**
- **Progression 15/12 from diagnosis, “aggressive” relapse**
- **Bortezomib given; GP alerted to enter on GSF register**
- **Good response, well over Christmas 2007**
- **Rapid relapse 03/2008 - Symptomatic, pain, fatigue etc**
- **Fully discussed in clinic – patient & husband understood & accepted situation; GP informed**
- **Strongly expressed wish to be at home & not hospital**
- **Elected not to come back to clinic; 3-4 telephone calls form GP – continuity & advice**
- **Palliative Care services at home**
- **Died at home late 04/2008**



***A successful outcome for all concerned/involved***

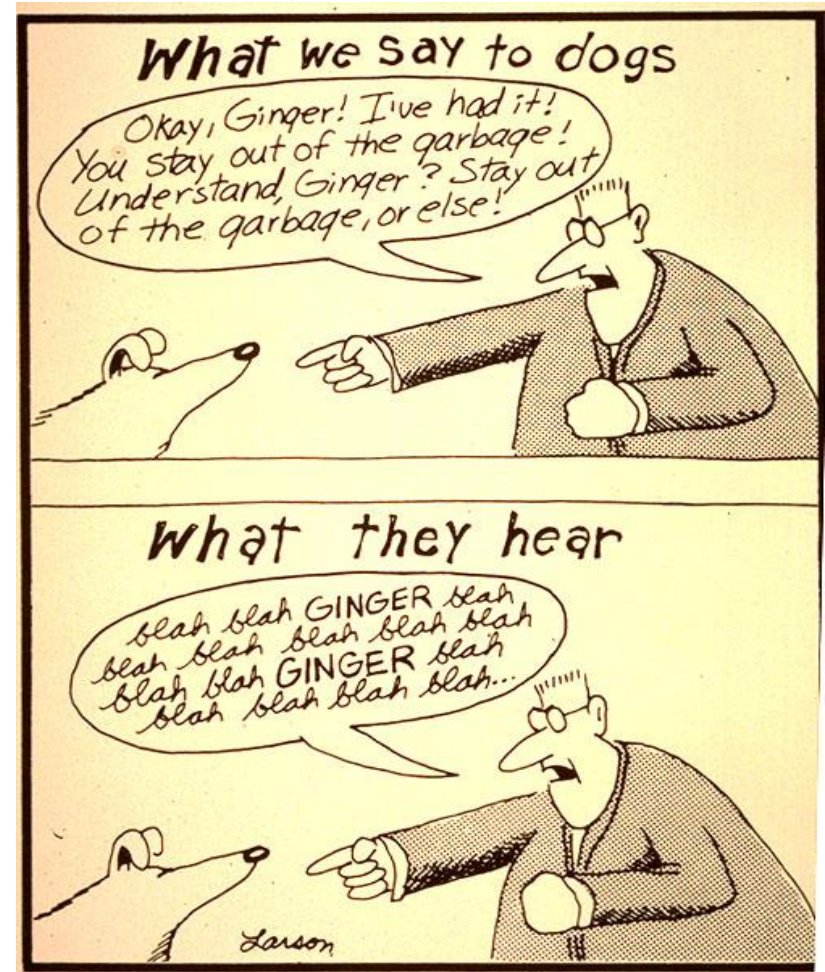


# **ENGAGING PALLIATIVE CARE – Temel et al NEJM, 2010**

- **Randomised comparison – metastatic lung cancer – at confirmation of diagnosis**
- **Standard Oncology Care**
- **Standard Oncology Care plus Palliative Care Introduction**
- **Survival duration, health care use, PROMS**
- **SURVIVAL – Standard care 8.9 months**
- **SURVIVAL – Standard care plus Palliative Care 11.6 months**
- **Better PROM data in Palliative Care group – improved depression scores etc**
- **“Aggressive EOL CARE” in 30/56 Standard group & 16/49 in Palliative Care group**
- **Resuscitation preferences recorded in 28% standard care group and 53% Palliative care group**

# Information to 1y care

- **Nature of treatment**
  - Curative
  - Disease stabilising
  - End of life
- **Information heading/code every letter**
- **Discussion about dying**
- **Prescribing information/direction**
- **Recommended condition specific information**
- **Outline care pathway/disease trajectory**
- **Co-morbidity**
- **Clinical team/MDT contact information**



# Improving communication ....

## Treatment Record Summary Template

### GP Contact Details

Dear Dr X

**Re: Add in patient name, address, date of birth and record number**

Your patient Mr/ Ms ----- has now completed the first part of their treatment management plan for their cancer. A summary of the treatment they have received to date and the ongoing treatment / management plan for them is outlined below. (pts name) is aware that this letter is being sent to you and has their own copy /does not have their own copy.

### Diagnosis:

**Significant Clinical Findings:** (NB include secondaries)

**Histology/ Staging/ Grade:**

**Date of Diagnosis:Summary of Initial Phase Treatment Delivered:Treatment Aim:** (

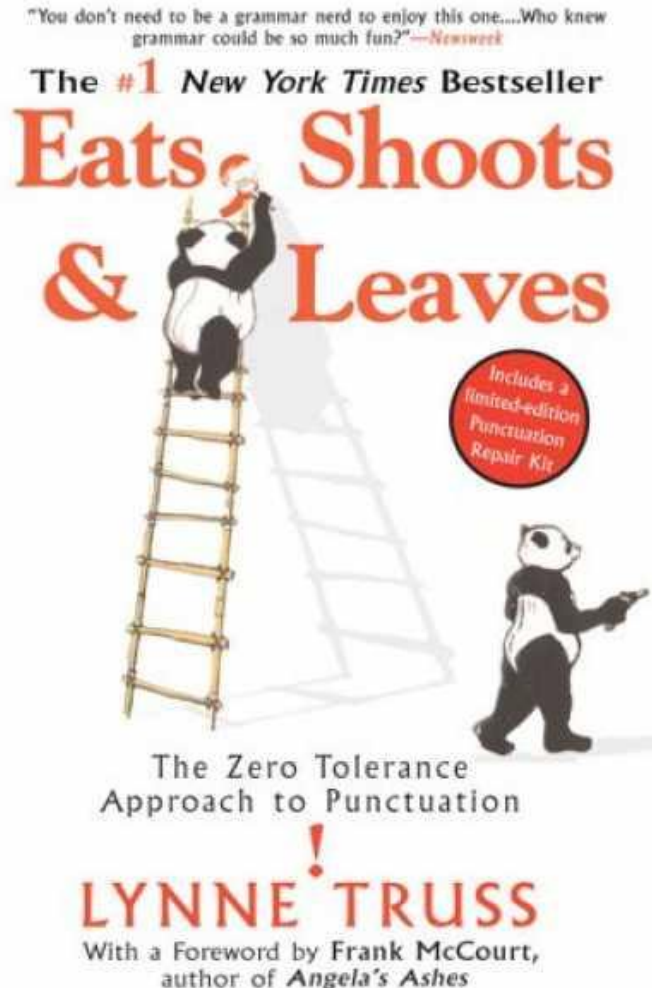
Please specify whether curative, disease/ symptom control or palliation)

**Possible treatment toxicities and / or late effects:***Need to stipulate which toxicities and / or late effects and appropriate action.*

**Treatment result** (Please specify eg complete remission/ residual disease etc)

ETC.....

# LANGUAGE & TERMINOLOGY



- **AFTERCARE**
- **SURVEILLANCE**
- **SYMPTOM & TREATMENT MANAGEMENT**
- **SUPPORTIVE TREATMENT**
- **REHABILITATION**
- **WELLBEING AND SELF-MANAGEMENT**

**?Zero tolerance to “follow up”**

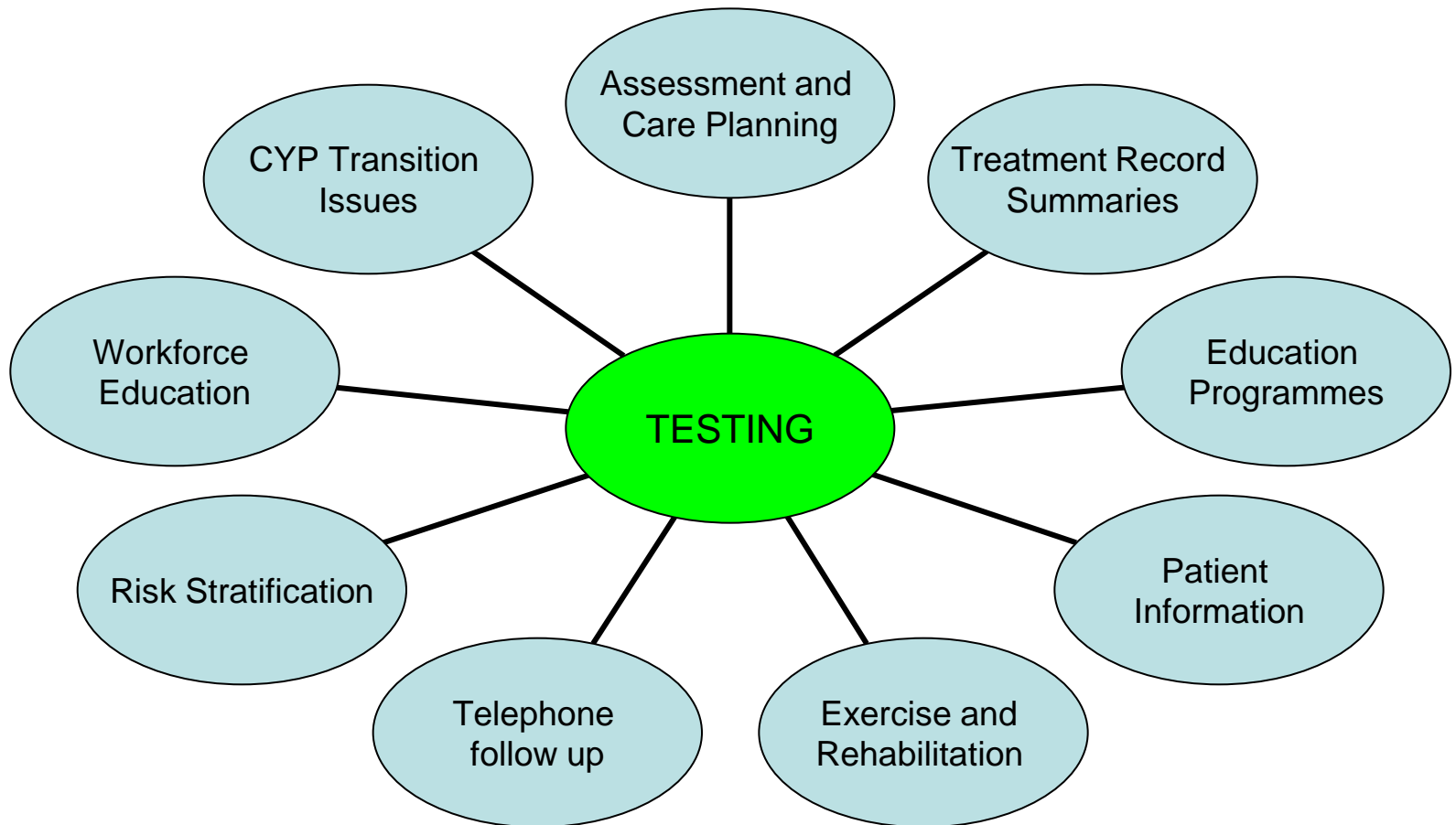
- *Shared clinician & service user understanding on “follow up”*
- *Need to articulate reasons & benefits – and educate commissioners*
- ***Future service provision***
  - *Who is seen, where and when*
  - *Follow up, treatment control by telephone, I-T links*
  - *Specialist nurse monitoring, community haematology nurses*
- *?No monitoring - but rapid access back into system*
- *Better support and information to primary care*
- *Engaging better with Palliative Care; the GSF - mutual benefits*

***Value patients' time & their carers***

***Reduce stress***

***Benefit the environment***

# Scope of Testing



# ***Baseline survey – Common Themes***

- ***Huge variation in follow up practice, mostly medically led and continuing for years***
- ***Little evidence of holistic risk assessment especially for those with disease recurrence, or late consequences of cancer treatment***
- ***Many with ‘cured’ or ‘incurable’ cancer with prognosis in years rather than months***
- ***Little evidence of personalised care plans***
- ***Variable level of re-access to specialist support***
- ***Patients have little choice or control***
- ***Information does not always meet patient needs***
- ***Patients are unclear who to contact if they have problems***
- ***3<sup>rd</sup> sector organisations offer a wide range of support services***
- ***Services for young people >18 not as good as paediatric based services***
- ***Education and entry into employment a key issue for CYP***



## *Learning so far ....*

- *ACP - valuable experience for patients and staff but requires planning, time, space and skill*
- *Care plans need to be ongoing, meaningful and useful to the patient and those supporting them*
- *Treatment Record Summaries improve communication between 1° and 2° care, are valued by GP's and continue to evolve*
- *Proactive, informed transition across the pathway is crucial*
- *Education options may need to be available in a number of formats – courses, events, one to one*
- *Care co-ordination in aftercare needs to be a function not an individual*
- *Need earlier identification of those who may require additional support*
- *Huge opportunities for IT solutions*



# White Paper & N.C.S.I. & “C.R.S. Refresh”

- **Empower patients** ..... **“no decision without me”**
  - Supported self-management
  - Personalised assessment and care-planning
  - Health & well-being reviews
  - Education courses
- **NHS Information Revolution**
  - Communication strategies
  - Tailored information and personalised care planning
  - Automated surveillance
  - Use of novel technology
- **Generate information from patients themselves**
  - Patient experience surveys      *Picker*
  - Include P.R.O.M.S. in aftercare pathways
  - National Cancer Survivor Experience Survey
- **Development of Pathway Tariffs**
  - “Whole” pathway approach to transformation of care
  - Move away from “payment by results” for aftercare
  - Bundles of risk-stratified aftercare

# Next Steps

- ***Establish prototype sites to test complete pathways in 5 main tumour groups (Breast, Prostate, Lung, Colorectal, Head and Neck, ?Myeloma)***
- ***Complete Economic Evaluation to understand the pattern and cost of current care***
- ***Develop robust, quality assured automated solutions for surveillance***
- ***Design and prototype care coordination functions that support effective self management and consistent care delivery across organisational boundaries***
- ***Develop ACP and Treatment Summary processes***

# The service delivery challenges

<b><i>Current service</i></b>	<b><i>Evolving model of care</i></b>
<b><i>Geared towards acute conditions</i></b> <b><i>Hospital centred</i></b> <b><i>Nurse dependent</i></b> <b><i>Episodic care</i></b> <b><i>Disjointed care</i></b> <b><i>Reactive care</i></b> <b><i>Patient as passive recipient</i></b> <b><i>Self care infrequent</i></b>	<b><i>Geared towards long-term conditions</i></b> <b><i>Embedded in communities</i></b> <b><i>Team based</i></b> <b><i>Continuous care</i></b> <b><i>Integrated care</i></b> <b><i>Preventive care</i></b> <b><i>Patient as partner / empowered</i></b> <b><i>Self care encouraged / facilitated</i></b>

# Cancer Reform Strategy “refresh”

- *What are the most important outcomes.....?*
  - *What actions do we need to achieve these.....?*
  - *What metrics might we use to measure ...?*
  - *What incentives would drive the change.....?*
  - *How can we do this with NO additional funding.....?*
- ***Move away from process measures***
  - ***Move towards outcome measures***
  - ***Patients’ experience of care***
  - ***Commissioning pathways***

...when will we get the message?



**Hippocrates of  
Cos,  
c 460 B.C. 377 B.C**

***“It is not enough for the physician to do what is necessary, but the patient and the attendants must do their part as well, and the circumstances must be favourable.”***