

National Cancer Survivorship Initiative

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- Background
- NCSI and CYP
- Emerging Principles
- Enablers and next steps

Why bother?

- 2 million living with and beyond cancer in UK
 - 1.6 m completed therapy
 - Prevalence increases by 3.2% p.a.
 - **4 million in 20 years**
- Follow-up & support
 - Prevention, early detection and management
 - Recurrence
 - 2nd malignancy
 - Late complications
 - physical
 - psychological
 - social

Who are the two million cancer survivors?

Sex / Age / Site	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60
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0-17	16,000	0.8
18-64	774,000	38.7
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Colorectal	250,000	12
Lung	65,000	3
Breast	550,000	28
Prostate	215,000	11
Other	920,000	46

CYP v Adult Survivorship

- Fewer late recurrences
- Growth & Development
- Damage to developing organs
- Transition to independence

CYP Background

- 40,000 survivors childhood cancer in UK
- Life years at stake are 2nd only to Breast Ca
 - Years at risk/case diagnosed under 24 years 52.8
 - Total years at risk 178,613 (UK incidence figures 2005)
- NICE IOG recommends lifelong contact with cancer centre
- 50% lost to follow-up

- Follow up strategies vary
- Is all follow-up necessary?
- Lack of capacity to continue model **4 million!**
- *Actually*

Not always necessary

Not always convenient

Not personalised/risk stratified

empty episodes

What Are We Trying to Achieve?

- Improve the quality and effectiveness of service delivery
- Improve quality of life for those living with and beyond cancer

*not only adding years to live,
but adding life to years*

NCSI

- Embedded in Cancer Reform Strategy Dec 2007
- Partnership launched between DH and cancer charities Sept 2008
 - 7 work streams including CYP (linking with CLIC Sargent & TCT)
 - 10 CYP test sites
 - Models of care + care co-ordination
 - Tx summaries and care planning
 - IT/Automated surveillance
 - Transition
 - Lost to follow up
 - Risk assessment & stratification
- NCSI Vision Jan 2010
www.ncsi.org.uk

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

Emerging Principles

- Risk Stratified pathways of care rather c.f. one size fits all
- Dynamic **personal care plan** which arises from an assessment of the disease, the treatment, and the individuals personal circumstances
- **Information provision** should meet individual needs and should be timely, accessible and promote confidence, choice, and control
- Individuals should be **encouraged to self manage with support** and rapid access to appropriate professional when problems arise

Emerging CYP Principles

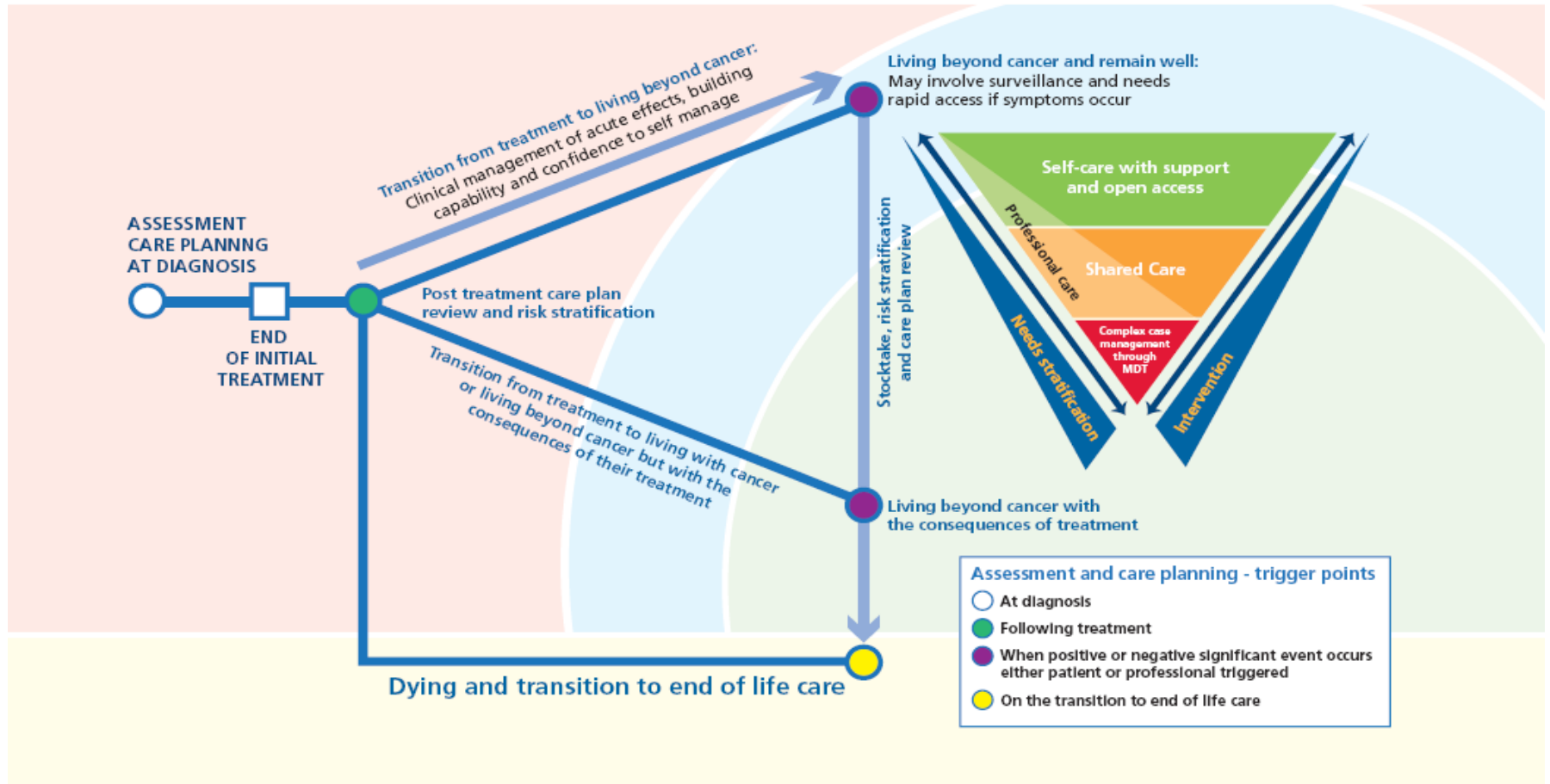
1. Introduction of care plans and treatment summaries
2. Emphasis on individualised care for all CYP cancer survivors
3. Alternative continuous aftercare rather than traditional models of care
4. Planned and informed transition
5. Safe, informed self management
6. Better use of technology to meet the needs of individual patients

Requirements for Successful Change in Philosophy of Care

- Patient empowerment
 - Education risks, routes to care
 - Ownership of information
- Seamless information exchange & communication
 - 1⁰, 2⁰, 3⁰ care and service user
- Standardised after care services
 - Responsive to requirements of the survivor and 1⁰, 2⁰ carers
 - Rapid re-entry into the appropriate part of the system

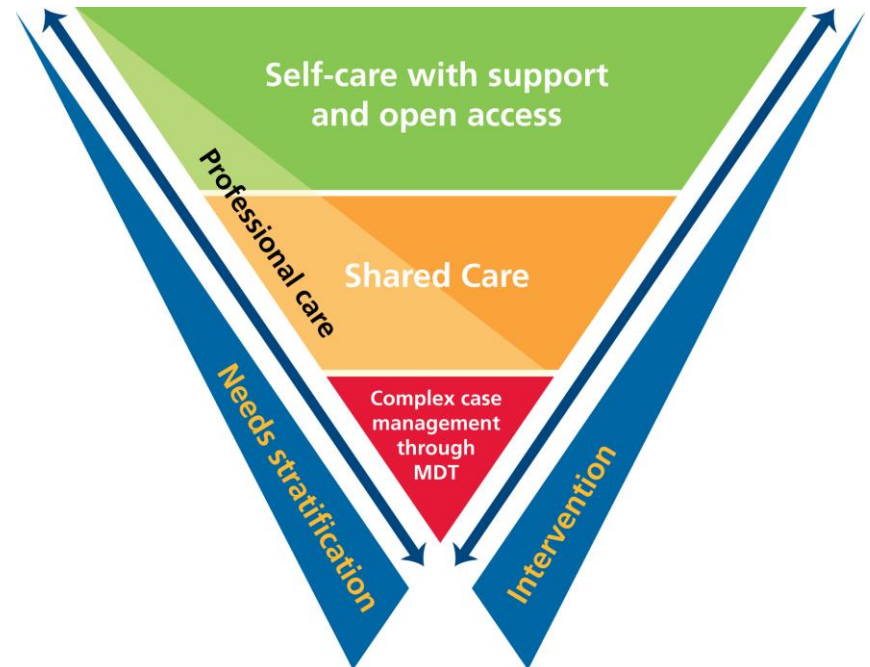
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Model of Care: Living With and Beyond Cancer



Risk Stratification

- Self-care
No routine OPA
Ability to re access system with/without GP
- Planned co-ordinated care
Planned reviews
Hospital, community , telephone
Clinical exam
Significant co-morbidities
Unable to self manage
- Complex care model
Complex complications or symptomatic needs
Rapidly changing health



Risk Stratified Model of Care

CYP risk stratification

- UKCCSG 2001 Wallace levels 1-3
- Evidence base
 - Interrogate BCCSS database to identify statistical relationships between disease and treatments received and health and social outcomes
- Refine levels of risk stratification

- Empower patients *no decision without me*
 - *Supported self-management*
 - *Personalised assessment and care-planning*
 - *Transition*
 - *Education courses*

- *NHS Information Revolution*
 - *Communication strategies*
 - *Tailored information and personalised care planning*
 - *Automated surveillance*
 - *Use of novel technology*

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

- Generate information from patients themselves
 - *Patient experience surveys*
 - *Include P.R.O.M.S. in aftercare pathways*
 - *National Patient Reported Outcome Survey of Cancer Survivors*
- *Development of Pathway Tariffs*
 - *Move away from “payment by results” for aftercare*
 - *Bundles of risk-stratified aftercare*

Enablers

- Awareness and education
- Evidence to identify what is being done well & what needs to improve
- Innovation
 - Automated surveillance
 - Education programmes
 - Care co-ordination
 - Exercise programmes
- Sensitivity to current economic climate
 - Enhanced efficiency & productivity
 - Caution re cuts to follow-up without investment in “enablers”
 - Increased partnerships between NHS and 3rd sector?

Lifestyle change more important for cancer survivors than others



Obesity

Dietary fat intake



Exercise

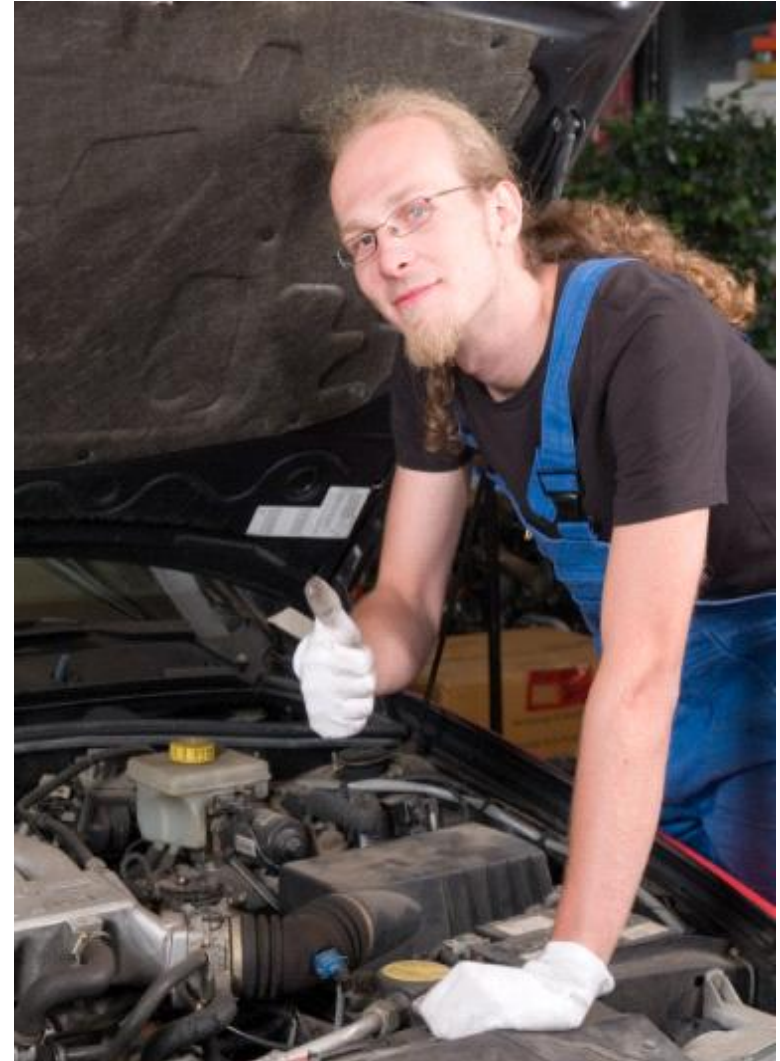
Smoking



Health and well being clinics offer opportunities to learn more than how to manage their disease

Supporting patients return to work

- Testing model of vocational rehabilitation through pilots.
- Work underway in providing support for employers.
- Study into patient experience of DWP programmes.
- Developing thinking about carers' issues.



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NCSI CYP QUIPP(P)

QUALITY
INNOVATION
PRODUCTIVITY
PREVENTION
(PATIENT INVOLVEMENT)

Huge amount of evidence to support development of new models of care and pathways

Building the evidence: Developing the winning principles for children and young people

www.improvement.nhs.uk

NCSI economic analysis (PROVISIONAL RESULTS)

- Case note review (n=100) individuals aged 18+ y and >10y from completion Tx

£647 over 5 years long term follow-up

- Wallace level 1 £387
- Wallace level 2 £597
- Wallace level 3 £905

- No significant reduction in costs the further out from therapy
- 7% events unplanned (greatest for level 3 patients) accounting for 10% costs

- Adult cancer FU from end of therapy

£1,554/patient over 5 years

Cost of hospital care for individuals completing Tx in the last 5 years £375 million pa

9% events unplanned accounting for 39% of costs

Service Transformation

- Quality
 - Enhanced access to information
 - Diagnosis, treatments, complications, risks, surveillance
 - Survivor & all components of health economy
 - Rapid access to specialist support & advice
- Productivity
 - Reduce unnecessary “empty” episode
 - Reduced “unplanned” activity
 - Automated surveillance
 - Seamless information exchange
 - 1⁰, 2⁰, 3⁰ care and service user

Survivorship Summary

Exciting opportunity to pro-actively influence the delivery of care to a rapidly increasing percentage of the population

Challenge to develop practical, sustainable evidence based pathways offering enhanced quality and productivity

Need sophisticated commissioning with investment in some areas resulting in savings in others

Many of the enablers & skills for a generic network-wide approach have been developed