CCN

central cancer network

www.centralcancernetwork.org.nz

Taking Survivorship Care Planning Forward in NZ

NZ Guidance for Improving Supportive Care

Survivorship refers to the period of time extending from the time of diagnosis through to death….

In New Zealand the period is divided into acute, extended and permanent phases.

Objectives

1. All people living with cancer long-term have their continued care and support needs routinely assessed at each critical point throughout their cancer service pathway.

1. All people living with cancer long-term receive a planned approach to their continued care and support that includes needs assessment, goal setting, an ongoing care plan, regular evaluation and referral to appropriate specialist support and care services.

Objectives (cont)

3. Continued care and support services are readily accessible, and provided in a timely and acceptable manner.

4. Health professionals and support workers working with people affected by cancer receive culturally appropriate education and training that enables them to assess the person's continued care and support needs and to make appropriate referrals to specialist services.

Late Effects Assessment Programme (LEAP)

Clinic Aims:

- All young people transition from active treatment and disease surveillance to long term follow-up with an end of treatment summary.
- Individual risk-based health surveillance
- Psychosocial / neuropsychological assessment & support as required
- Information/ resources on specific late effects and future health risks
- Access to resources to support transition to adult health care services and/or knowledgeable " self care".

UK

The NHS in the UK sees 5 key shifts, in the approach to care, as necessary to achieve survivorship goals:

- A cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and wellbeing after cancer treatment

- A shift towards assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences

UK

- A shift towards support for self-management. This is a shift from a clinically led approach to follow up care to supported self management, based on individual needs and preferences and with the appropriate clinical assessment, support and treatment

UK

- A shift from a single model of clinical follow up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease

- A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of patient reported outcome measures in after care services

CCN Coordinated Approach

The region takes a coordinated, programmed approach to survivorship development across the following areas:

- Survivorship Care Planning – the specific assessment and planning activity that occurs when a patient transitions from active care; liken this to a Last Specialist Assessment (LSA)
- Survivorship support programmes – programmes which provide education and support for patients and their families in the survivorship phase
- Vital link that ensures patient is connected to GP and community based services

Principles

- Consumers (patients and carers) must be involved in all facets of this programme of work ie take a co-design approach
- Maori must be involved and a focus on identifying and addressing equity issues needs to occur
- Projects within this programme of work should build as much as possible on existing activities and resources, both nationally and internationally

Principles

- Focus on local and regional development but with the aim of informing and influencing at a national level
- Evidence based approach to be taken where the evidence is available
- Evaluation must be built into all project areas
- Promote and support self-empowerment of consumers

Potential Activities

Potential activities	Who might lead	Comments
Establish a regional Survivorship Work Group to advise on, lead and coordinate activities	CCN	CCN provides secretariat support
Draft a set of standards for survivorship care planning	Work Group	Seek national endorsement
Identify survivorship related projects, programmes and care plans currently underway in the region. Publish a directory on the CCN website and provide to other RCNs	CCN	Example - UCOL clinic where there is a MDT focus with patients who have chronic disease, or chronic pain, and are managed through exercise as a part of their treatment plan

Potential Activities

Focus areas being discussed include: • Drafting a post treatment care plan model • Providing copies of discharge letters to patients • Rehabilitation and wellbeing programme	WBCC / Cancer Society / Consumers	Consider joint approaches across the two cancer centres and Cancer Society Divisions as appropriate Consider how to link with CSNZ patient diary
Focus areas being discussed include: • Piloting a survivorship care plan for breast cancer patients • Establishing a late effects clinic • Health promotion action research	RCTS / Cancer Society / Consumers	

Potential Activities

Assess the resource Adult Cancer Survivorship - A Self-Learning Resource for Nurses (www.cano-acio.ca) for suitability for use in NZ	CCN Regional Cancer Nurse Directors and Regional Cancer Nursing Group (to be estab)	If appropriate, include the development of a training plan to deliver this across the region within the regional nursing strategy
Consider a project relating to Men's survivorship and apply to CSNZ Men's Health Fund for support	Work Group	Link with Cancer Society Men's health committee
Manawatu Cancer Society works with the Advisory Group to identify how they can best utilise $25K funding assigned to a project to progress survivorship	Manawatu Cancer Society	
Link with development occurring at a national level as the Supportive Care implementation plan is rolled out.	CCN	Ongoing - ensures alignment Informs work at a national level
Link with NHITB work to progress Shared Care Records and Patient Portals	Steph (CCN) - NHITB Consumer Rep	Ongoing - how this work could be an enabler for care planning in the future

Survivorship standards?

- What would be the value of developing a set of standards to guide survivorship planning in NZ?

Workshop standards