Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process

YOUTH CANCER SERVICE | canteen

A survivorship care process, screening tool and care plan developed to improve psychosocial outcomes for cancer survivors aged between 15 and 25 years. The process was developed in conjunction with AYA cancer survivors and Australia's leading AYA clinicians.

Youth Cancer Service SA/NT
Mail DP 11, Level 4 East Wing
Royal Adelaide Hospital
North Terrace
Adelaide
South Australia 5000
youthcancer@health.sa.gov.au

Distress Thermometer Screening Tool FIGURE (DIS-A) reproduced and adapted with permission from the NCNN Clinical Practice Guidelines in Oncology (NCCN Guidelines™) for Distress Management V.1.2011. ©2010 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines™ and illustrations herein may not be reproduced in any form for any purpose without the express written permission of the NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. NATIONAL COMPREHENSIVE CANCER NETWORK®, NCCN®, NCCN GUIDELINES™, and all other NCCN content are trademarks owned by the National Comprehensive Cancer Network, Inc.

This document was prepared by Dr Susan Palmer (MPH, M. Psych, PhD) for the SA/NT Youth Cancer Service.

The suggested citation for this document is:

Youth Cancer Service SA/NT (2012). Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process. Adelaide: Youth Cancer Service SA/NT.

This document is a general guide to best practice psychosocial survivorship care for adolescent and young adult survivors of cancer. The issues identified and the processes recommended are focused on building healthy psychosocial functioning following treatment completion. This process is a companion to the ongoing medical monitoring and late effects management of survivors. The psychosocial survivorship screening tool and care plan are designed to be implemented as part of a holistic multidisciplinary approach to AYA survivorship care. They are not to be used as a substitute for clinical judgment or multidisciplinary team planning.

Foreword

In recognition of the need for age appropriate care for adolescents and young adults diagnosed with cancer, the Australian Government provided CanTeen with $15 million for the delivery of the Youth Cancer Networks Program from 2009 to 2012. This was followed with an additional $17.88 million commitment from 2013 to 2017. As well as providing medical and psychosocial support across Youth Cancer Services (YCS) in five jurisdictions, the program funds several national projects. One national project was the development of the Adolescent and Young Adult Oncology Psychosocial Care Manual in 2011. This manual is a landmark national guideline for health professionals supporting young people receiving treatment for cancer. The manual is used by the Youth Cancer Services across Australia and guides the development of a comprehensive individual plan of psychosocial support, intervention, and age-appropriate care.

In appreciation of the fact that psychosocial concerns do not cease when treatment ends, the SA/NT YCS developed a partner manual, the Adolescent and Young Adult Oncology Survivorship Care Process. This manual recognises that healthy psychosocial survivorship entails supporting the patient as they move beyond treatment and adjust to life after cancer through screening and care planning during this critical time of transition.

Together, the two psychosocial manuals provide a clearly articulated pathway for the provision of psychosocial support across the cancer care continuum, enabling the provision of best practice and age-appropriate supportive care.

Peter Orchard
CEO, CanTeen Australia

Acknowledgements

Thank you to everyone listed below who willingly gave their time and expertise as members of the working parties and clinical reviewers in the development of the Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process. In particular thanks go to our project consultant Dr Susan Palmer. We would also like to thank the clinicians who piloted the Care Process and provided valuable feedback, including Kate Thompson and Lucy Holland from ONTrac@PeterMac and Allan Hayward from the SA/NT Youth Cancer Service, as well as the national Youth Cancer Service team, including Pandora Patterson, Janine McDonald, Hannah Baird, Alexandra Crowley and Peter Orchard, and the staff of the other Youth Cancer Services from around Australia.

This initiative was funded by the Australian Government under the Youth Cancer Services program.

Project Steering Committee

- Susan Palmer
- Michael Osborn

Clinical Working Party

- Michele Blohm
- Sharon Bowering
- Janine Deevy
- Marianne Fenton
- Anne Gannoni
- Priscilla Gates
- Lyndal Gray
- Michael Hopkins
- Fiona Maguire
- Belinda Matigian
- Gordon Miles
- Gillian Myles
- Cath O'Dwyer
- Michael Osborn
- Emma Sayers
- Orietta Simons
- Kendall Stratton
- Aaron Thompson
- Kate Thompson
- Danielle Tindle
- Olivia Urbaniec
- Esther Yeoman

Patient Working Party

- Lucy Lysenko
- Jessie Macallan
- Casey MacKay
- Anders Wong

and those who chose not to be named

Contents

Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process

Building on the Australian Adolescent and Young Adult Oncology Psychosocial Care Manual (CanTeen, 2011), the Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process, Screening Tool and Care Plan aim to improve the survivorship care provided to Australian survivors of AYA cancer. The process addresses a range of issues associated with psychosocial recovery and post-treatment functioning within a self-management framework. The process does not address the medical late effects or include an individualised treatment summary.

It is recommended that this psychosocial survivorship care process is incorporated into standard AYA patient management in Australia. While the process is necessarily flexible to meet the needs of individual patients and treating institutions, a standard psychosocial survivorship screening tool and care plan ensures that all young people have access to the same information and a minimum standard of psychosocial survivorship care – regardless of their treatment location.

Survivorship

Over the past decades, the marked improvement in cancer survival rates has led to a groundswell of interest and research in survivorship care. While various definitions of survivorship exist within the literature, for the purpose of this clinical process *survivorship begins on the first day following treatment completion and continues until two years post treatment completion.* While young people may identify as a survivor before the final day of treatment and well in to their future, this 24 month time frame was determined by the group of AYA clinical experts (a full list is at the back of this document) as crucial to developing the positive foundations for healthy psychosocial functioning into survivorship.

Survivorship Care

One of the impacts of this increased recognition of cancer survivorship is a change in the way this issue is approached during the treatment phase. It is becoming clear that the *preventative* management of problems frequently experienced during cancer survivorship leads to the best outcomes for post-treatment adjustment. Consequently it is preferable that potential survivorship issues are identified throughout the treatment journey and proactively addressed rather than leaving them to accumulate until the end of treatment.

This requires a new approach to patient management and changes in clinical care provision. At the centre of this change is an emphasis on the individual assessments and care planning. In the United Kingdom, the National Cancer Survivorship Initiative (NCSI) has identified five areas of change required within their current model of cancer care delivery in order to make significant improvements to current survivorship outcomes. These are: (i) a greater focus on recovery, health and wellbeing for people living with and beyond cancer, (ii) a move towards assessment, information provision and personalised care planning, (iii) a move away from a clinically led approach to follow-up care and towards 'supported self-management', (iv) tailored support that focuses on early recognition of, and preparation for, the consequences of treatment, and (v) a shift towards emphasising the individual needs and experiences of cancer survivors (p.7). This approach has been fundamental to the formulation of the Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process, Screening Tool and Care Plan.

Psychosocial survivorship needs of AYA patients

Supporting healthy psychosocial survivorship for AYA patients entails more than just monitoring and responding to the physical late-effects of treatment. It involves educating, informing and supporting the patient to move beyond their treatment phase and adjust to life after cancer. In doing so, the clinical team needs to acknowledge and address all of the issues, positive or negative, that can be traced back to the cancer experience and have the potential to impact upon the life of the young person in to the future. Although research conducted on AYA survivors is limited, it is widely accepted that the areas of peers, intimate relationships, independence, family, fertility, education and finances are important areas to address in the provision of holistic survivorship support and monitoring (Palmer and Thomas, 2008).

Throughout the treatment phase it is incumbent on the treating team to be mindful of aspects of the young person's life that require additional supports in order to ensure that their psychosocial survivorship is not compromised. This may include supporting the young person to (i) continue with their education, (ii) maintain relationships with peers, (iii) manage changes in family relationships, (iv) retain a level of independence, and (v) continue with their developmental tasks despite their cancer diagnosis and treatment. This process can be supported through the use of the *AYA Psychosocial Assessment and Care Process* (CanTeen, 2011).

If this level of care can be achieved throughout treatment, the young person is in the best position to develop a solid foundation to assist in their transition to life after cancer treatment. If not, the young person is faced with the difficult task of re-integrating back into life and attempting to re-commence developmental tasks at the point of treatment completion. At a time when they may just be realising the enormity of their experience and the ongoing impact that it may have on their life, this is an added and unnecessary burden.

Central to this process of psychosocial survivorship care is the promotion of self-management. It is an essential component of healthy psychosocial recovery that the young person is able to take responsibility for their future and manage their survivorship. In order to achieve this, once all matters of clinical significance requiring specialist management have been addressed, the young person must be supported to (i) formulate their future goals, (ii) identify areas of need and issues requiring support, and (iii) address these within an individualised *AYA Psychosocial Survivorship Care Plan*. The care plan will then form the foundation of their supported recovery.

The role of a trusted General Practitioner (GP) to support the young person through this transitional period and throughout their self-managed survivorship is vital. As the young person moves away from the hospital environment, it is important that they have a trusted health professional available to assist and guide them when necessary. In most instances, a GP is best placed to play this role.

Development of the AYA Psychosocial Survivorship Process, Screening Tool and Care Plan

The *AYA Psychosocial Survivorship Care Process*, including the screening tool and care plan, was developed as part of a collaborative process incorporating the views of AYA cancer survivors and Australia's leading AYA clinicians.

The patient perspective was represented by a group of five AYA cancer survivors who were introduced to each other during an initial focus group and then formed a working party to provide ongoing guidance to the project. These young people, aged between 18 and 26, had been diagnosed with various cancer types between the ages of 15 and 21. On average, they had completed cancer treatment three years prior. They had been treated in a range of institutions, were continuing with their follow-up care and had previous contact with cancer support groups.

The clinical perspective was represented by a group of specialist AYA clinicians from around Australia. The original focus group consisted of 15 clinicians from all states except Western Australia. These 15 clinicians represented the lead AYA oncology treatment sites from Victoria, New South Wales, Queensland and South Australia and included experts in the fields of nursing, social work, psychology, paediatric oncology and late-effects. A working party that consisted of the original 15 clinicians, with the addition of a further eight experts who could not attend the focus group (including those from Western Australia), then informed the further development of the project.

Through the ongoing consultation and revision by these patient and clinical working groups, the *AYA Oncology Psychosocial Survivorship Care Process, Screening Tool and Care Plan* were developed.

Minimum standard of care

Due to the differing structures, resources, expertise, demographics and priorities within Australia's state-based health systems, it was imperative that the *AYA Psychosocial Survivorship Care Process* and accompanying tools be developed to enable flexible administration. While this need for flexibility has informed the process, it is essential that those working with AYA survivors are ever vigilant to the needs and expectations of these young people. The seven principal expectations identified within the literature and by the AYA survivors (see below) must be addressed regardless of the administrative process chosen to meet the needs of the clinical program.

The Seven Principal Expectations of AYA Cancer Survivors	
1	To return to a life that is 'normal' as soon as possible
2	To be empowered to take control of their survivorship
3	To be given the information they need to do this
4	To know what potential issues they need to look out for
5	To know that these issues are 'normal'
6	To know who to go to should they need extra support
7	To have someone who is there to help with any concern - "*Who is in my corner?*"

In delivering a minimum standard of psychosocial care to AYA cancer survivors, it is essential that these seven principal expectations are addressed. How the treating institution chooses to manage this is subject to the resources, structures and expertise available both within the treating team and the community. However, at a minimum, in order to address these expectations it is recommended that;

(i) general survivorship information is incorporated into standard patient management **throughout treatment**

(ii) specific psychosocial survivorship information is provided to the patient at **approximately two weeks prior to treatment completion**

(iii) a full survivorship consultation is conducted at **approximately six weeks post treatment completion**, and

(iv) further psychosocial survivorship screening is conducted **6 months and 12 months post treatment completion**.

Recommended skill level for administration

It is recommended that clinicians administering the *AYA Psychosocial Survivorship Care Process* have as a minimum, a degree in nursing, psychology, social work or medicine. Specialist interest in AYA health and communication skills training are an advantage. It is strongly recommended that the process is undertaken by hospital or health service staff, so that prompt referral can be made to an appropriate clinician in the event that significant issues are uncovered. All clinicians managing the psychosocial survivorship care of AYA patients are encouraged to connect with their local AYA oncology team for support and guidance (contact details are at the back of this document).

Assumed knowledge base for administration

In order to support the young person effectively in the self-management of their survivorship, the clinician conducting the *AYA Psychosocial Survivorship Screening Tool* and developing the *AYA Psychosocial Survivorship Care Plan* must (i) have a thorough understanding of the AYA life stage, (ii) be able to communicate well with young people, (iii) have the capacity to support them to explore their own solutions, and (iv) be aware of age appropriate resources, information and support. It is also preferable that the clinician has an understanding of the treatment experienced by the AYA and the ramifications of such treatment – physically, psychologically and socially.

In essence, the clinician doing the psychosocial assessment must have an understanding of where the young person has come from, what they have experienced and where they want to get to. Only then can an appropriate plan be developed to meet their needs. Clinicians looking for further education or training regarding the management of a young person should contact an AYA cancer service in their state (contact details are at the back of this document).

Noted exclusions

The medical late effects of cancer treatment are not addressed in the *AYA Psychosocial Survivorship Care Process*. The issues identified and the processes recommended are focused on building healthy psychosocial functioning following treatment completion. This process is developed to be a companion to the ongoing medical monitoring and late effects management of survivors.

The process focuses on the biopsychosocial impacts of cancer treatment in the period immediately following treatment until approximately two years post treatment. For those young people returning for follow-up care beyond the two year period highlighted within this process, this measure may not address all of their needs. It is recommended that an individualised clinical assessment is used to screen for unmet needs in these longer term cancer survivors.

The focus of this process is the cancer survivor. While it is recognised that the needs of the family will directly contribute to the survivorship experience of the young person, this measure does not specifically address the supportive care needs of other family members. These issues need to be addressed by survivorship teams on an individual basis.

Finally, these tools are designed to be implemented as part of a holistic multidisciplinary approach to AYA survivorship care. They are not the only factor in providing best practice survivorship care. They are not to be used as a substitute for clinical judgment or multidisciplinary team planning.

AYA Psychosocial Survivorship Care Pathway

Best-practice AYA Patient Management

This process begins with the assumption that best-practice AYA patient management, including psychosocial screening and assessment, individualised care plans, age-based referral, clinical support and information provision to support healthy survivorship, has been provided throughout the treatment period.

Psychosocial Survivorship Information

It is recommended that survivorship information relevant to the journey of the individual patient is provided at approximately two weeks prior to treatment completion or at the time of final treatment. This information should contain basic survivorship information, the survivorship care pathway for the treating institution, the next steps planned for the patient in relation to their survivorship, and details of who to contact with any survivorship questions in the time between treatment completion and their full survivorship consultation.

Psychosocial Survivorship Screening Tool

A full survivorship consultation is recommended at approximately six weeks post treatment completion. This consultation should involve the treating oncologist in some capacity and other members of the treating team as relevant. Along with the treatment summary from the medical team, the first survivorship screening tool is to be administered at this time point. The results of the screening tool will form the foundations for the survivorship care plan.

Dialogue between survivor and clinician

Psychosocial Survivorship Care Plan

The individualised survivorship care plan is developed following the administration of the screening tool. Depending on the process decided by the treating institution, and the level of need identified by the survivor, this can occur immediately following completion of the screening tool or at an agreed time over the next fortnight. The development of the survivorship care plan should not occur without in-depth dialogue with the young person and informed by the results of the screening tool. Time to do this thoroughly should be taken into account when determining institutional process. Based on the needs identified by the screening tool, three types of intervention are recommended.

Direct Support

This occurs in instances where the treating team is best placed to manage the areas of unmet need. Examples include regular psychological consultations for goal setting or educational support to apply for special consideration. This would be based on the resources and remit of the treating institution.

Information Provision

Many of the areas of unmet need can be addressed by providing appropriate AYA information. Pertinent topics include; *Individualised cancer and treatment information; Fertility support; Familial cancer; Psychosocial support; Education support; Support groups; Employment assistance; Financial support; Health promotion.* Survivorship teams should have ready access to such information.

Referral

Where needs identified are managed most effectively by external agencies, referral information should be provided in a timely manner. It is recommended that each treating institution has a referral directory of appropriate community supports. The referral information should be highlighted as part of the care plan and, once the initial contact has been made, managed by the young person.

The AYA Psychosocial Survivorship Care Pathway was developed in conjunction with the clinical working party and the patient focus group. The guidance provided in relation to timelines, consultations and professional involvement is designed to be flexible in order to meet the different resources and clinical structures within the various lead sites. The following chapters address in detail recommendations regarding the provision of information, the administration of the screening tool and the development of the care plan.

AYA Psychosocial Survivorship Information

Ensuring access to developmentally relevant information is an essential component of best-practice psychosocial survivorship care and central to the process of self-management. However, the provision of such information does not begin at treatment completion. These information guidelines are based on the assumption that appropriate information regarding the potential psychosocial impacts of cancer and its treatment - including the influence cancer has on returning to a 'normal life', the importance of maintaining connections with friends and family, the need to maintain future goals and forward planning – have been addressed with the young person throughout their treatment journey. This assists the young person to plan for their survivorship and identify areas of concern in a timely manner to ensure they can access support when required.

To date, there is no standardised age specific AYA psychosocial survivorship information. It is incumbent on each lead site to source or develop such information and ensure that it is available to their group of survivors.

Administration Guidelines

Accurate and timely health care information is necessary to maximise the health potential of cancer survivors (Horowitz et al., 2009). The following recommendations relate to the provision of psychosocial survivorship information at approximately two weeks prior to treatment completion. For many patients, this will be their final consultation with their treating team prior to their initial post-treatment consultation. It is essential that the treating team is mindful of the psychosocial information needs that may become relevant in this immediate period post-treatment completion and that they are addressed. Such information should support the young person during the early weeks of survivorship prior to their first post-treatment consultation where the screening tool and care plan will be administered.

For many young people, treatment completion has been the crucial goal of their cancer journey. Some may not have thought about what life might be like after treatment and, while transitions can be difficult, having appropriate information to prepare and normalise potential outcomes can assist. Furthermore, ensuring that the young person is aware of the survivorship care pathway can provide safety – particularly after a period of time living within the rigid structures of a cancer treatment protocol.

Psychosocial Survivorship Information Checklist

1	**Basic survivorship information.** This includes highlighting the common physical and emotional responses that can manifest post-treatment completion and suggestions on how to manage them. It should also include guidance about when to contact the treating team for additional support. Such information serves to prepare the survivor for responses they may experience and normalise these responses in the context of the survivorship process. It is also recommended that information regarding appropriate support groups and support agencies is provided at this time, regardless of whether it has been provided on previous occasions.
2	**Survivorship care pathway for the treating institution.** Each institution will have a different survivorship care pathway and it is incumbent on the treating team to provide the young person with details about 'what comes next'. Finishing treatment can be accompanied by a sense of abandonment as the young person leaves behind the hospital environment and staff that they had come to trust and depend upon. Knowing the plan for survivorship, and understanding that there will be some ongoing contact with the treating team, can provide comfort during this time and reduce feelings of anxiety, fear or abandonment. Included in the information regarding the care pathway should be the upcoming survivorship consultation, *AYA Psychosocial Survivorship Screening Tool* and *AYA Psychosocial Survivorship Care Plan*. It is recommended that the self-management approach to psychosocial survivorship is discussed in these early stages so as to prepare the young person for their role in moving forward.
3	**Survivorship appointment details.** Prior to treatment completion, the patient should be provided with the date for their next appointment. In the case when there are no medical appointments or tests required during the first weeks, the next appointment will be the survivorship consultation. The young person should know where to go, who they will be seeing and what they need to bring for the survivorship consultation.
4	**Details of who to contact with any survivorship questions.** It is not uncommon for the emotional processing of the cancer experience to begin following treatment completion. Young people who may have indicated they were coping well at treatment completion may find themselves requiring additional information and support during the first weeks of survivorship. It is important that contact details are provided for this support. This person plays the role of the 'lead clinician' during the first six weeks of survivorship prior to the survivorship consultation. The role is to answer questions, direct the young person to further support or information as required and address any other issues that may arise. This process is directly addressing the need for the AYA to feel that they have *'someone in my corner'* and promotes a proactive response to concerns as they arise rather than waiting until the survivorship consultation.

AYA Psychosocial Survivorship Screening Tool

The clinical benefits associated with the use of an age appropriate psychosocial survivorship screening tool are multifaceted; it identifies levels of distress so that support can be offered, it identifies areas of concern to address preventatively prior to a crisis developing, it opens the door to discussion by normalising outcomes, it proactively highlights areas of information that may assist, and it ensures the process is forward looking by identifying future goals. Furthermore, a standardised psychosocial survivorship assessment assists AYA teams to triage their resources more effectively as it identifies those young people with the greatest level of need for immediate support and highlights survivors whose needs may be met outside of the treating institution.

The primary focus of this *AYA Psychosocial Survivorship Screening Tool* is to identify (i) what are the main issues of concern for the young person, (ii) what their goals are for the future, and (iii) what information they require to support them to address their issues of concern and achieve their goals. It is these aspects of the screening tool that will form the foundations of a positive and future focused care plan. Like the *AYA Psychosocial Screening Tool* before it, the *AYA Psychosocial Survivorship Screening Tool* is a five step process. These steps are designed to identify the support needs of the young person, promote supported self-management, and focus on a positive survivorship through future planning. These five steps are; (i) the distress thermometer, (ii) the check list of 'areas of concern', (iii) the identification of future goals, (iv) the tick box for information provision, and (v) the signatures. Each of these sections has a role to play in supporting the development of an individualised psychosocial survivorship self-management care plan.

It is critical to appreciate that the screening tool is only an initial component of the care process, and that screening without subsequently addressing the identified issues is likely to be ineffective and may even be harmful. Rather, **the screening tool should help identify topics to be addressed in the subsequent dialogue between the patient and the clinician, and to guide the development and enacting of the care plan.** This is also important because some patients may attach different meanings to different items. For instance, a patient ticking the item "Sexual Concerns" may have concerns about their current physical sexual function, future sexual relationships, sexual orientation, or other issues. Discussion of these topics may also facilitate a health promotion discussion on safe sex practices.

Administration Guidelines

The *AYA Psychosocial Survivorship Screening Tool* is not to be used to the exclusion of clinical discussion and exploration of needs. It has been designed to complement and support the consultation process by ensuring the prioritisation of issues and acting as a prompt to ensure all areas of survivorship care are addressed. It can also assist in setting the tone of the consultation by focusing on future goals and addressing the barriers to achieving these goals.

It is recommended that the administration of the screening tool occurs as part of a complete post treatment consultation. This consultation should involve the treating oncologist in some capacity and other members of the treating team as relevant. It is recommended that a full treatment summary from the medical team is made available at this point to complement the information provided as part of the survivorship management.

The *AYA Psychosocial Survivorship Screening Tool* should first be administered to all AYA survivors at approximately six weeks post treatment completion. The particulars relating to the administration of the screening tool - for example, in a patient waiting room or in the clinical setting – are to be determined by each treating team commensurate with available resources. The onus is on each lead site or treating team to determine the best process to meet their needs. While some services may elect to mail the screening tool to patients prior to the consultation, we recommend that it should be completed in the clinic or waiting room, so that an appropriately-trained clinician is available to ensure that there is no misunderstanding of the particular items and to alleviate any anxieties that the tool itself raises, for example suicidal ideation. The following additional points should be considered when developing this process.

Determining process for administration

1. Ensure all of those working with the young person understand the need for psychosocial survivorship screening and support their role within the survivorship care process (for example, oncologists, psychologists, AYA teams, CNCs, GPs, etc).
2. Look at ways to build the psychosocial survivorship care process into existing patient management so as to avoid adding another ‘layer’ of care.
3. Address the practicalities. For example, ensure that survivors have enough time available to undertake the screen either during, or prior to, the survivorship consultation process. Make sure there is a quiet space if needed. Ensure all documentation is available.
4. Identify which team members are best placed to do the screening and ensure they understand the process.
5. Integrating new tools into practice takes some adjustment. The initial plan of administration does not need to be the final method – it can be a process of learning and amending.

Distress Thermometer (Step One)

The Distress Thermometer (NCCN, 2011) is an objective measure of patient distress. It asks the question “How distressed have you been over the past week on a scale of 0 to 10 (where 0 is equal to no distress and 10 is equal to extreme distress)?” While it is anticipated that the ongoing implications of the cancer experience will create a level of distress for many young people, the distress thermometer aims to identify those patients suffering from levels of distress that require a specific intervention. The intervention required is then determined by the accompanying needs assessment which lists a number of potential ‘causes’ of the distress. As the distress thermometer is an essential component of the aforementioned *AYA Psychosocial Assessment and Care Process* (CanTeen, 2011), it should be familiar to both the AYA survivor and the clinician administering the screening tool.

The NCCN (2011) Distress Management Guidelines recommend that a score of less than 4 is equivalent to mild distress and represents a level of ‘expected’ distress given the circumstances. Scores of 4 or more indicate levels of higher distress that require specific interventions. It is important to note, however, that these ‘cut offs’ are for adult patients and their applicability for AYA survivor populations are yet to be determined; clinical caution is recommended.

Needs Assessment (Step Two)

The needs assessment section of the *AYA Psychosocial Survivorship Screening Tool* (titled Specific Areas of Concern or Adjustment) identifies eleven specific areas of concern and includes a section to highlight any worries or concerns not identified in the check list. The areas covered are (i) physical, (ii) emotional, (iii) social, (iv) concentration, (v) fertility, (vi) impact of experience, (vii) family, (viii) lifestyle, (iv) survivorship, (v) employment, (vi) education. These topics were developed based on issues identified in the literature, the feedback from the clinical working party and the needs identified by the focus group of AYA survivors. Survivors completing the needs assessment indicate which of the areas identified have been of concern over the past month by marking the relevant items. These items then become the issues to address when developing the care plan.

Future Goals (Step Three)

Survivorship is about life after cancer. It is essential that the young person is supported to move on with their life in the best way they can. To do this, an individualised approach that takes into account their future goals is important. This section of the screening tool asks the young person to identify what their goals are for the future and what they want to go on to achieve. These goals will be central to the process of developing the survivorship care plan.

Information Required (Step Four)

The topics identified in the information 'tick box' section at the bottom of the screening tool are those highlighted by the working parties. These areas of information - while not considered being essential to post-treatment adjustment for all survivors - have the potential to negatively impact survivorship functioning if not addressed. By providing the 'tick box' section, the young person is given the opportunity to identify areas where they need further information. Furthermore, it acts as a prompt for discussion and it provides the clinician with a reminder of information that should be discussed during the consultation.

To date, there are no standardized AYA specific resources that cover each of the highlighted information topics. Each institution has the responsibility to create their own information resources that meet the requirements of the *AYA Psychosocial Survivorship Screening Tool*.

Signatures (Step Five)

The signature section at the bottom of the page is the final section of the screening tool. This is included to promote the self-management of the survivorship care process. When completing the screening tool it is important that the clinician is clear and honest about what ongoing psychosocial survivorship support (if any) will be provided by the treating team and where the primary psychosocial support for the survivor will now be provided. It is recommended that a discussion explaining the essential role of a trusted GP in providing ongoing psychosocial survivorship support is commenced at this point. This will be further highlighted during the development of the care plan.

The outcomes of the consultation and the next steps should be summarised and, if time allows, the *AYA Psychosocial Survivorship Care Plan* should also be completed as part of this consultation. If not, it is important that another time is made for the young person to come in and discuss what the plan will be. The dual signatures represent the shared understanding between the patient and the clinician that the next steps have been discussed and agreed upon.

AYA Psychosocial Survivorship Care Plan

The development of a comprehensive, survivor-led psychosocial care plan is central to the AYA psychosocial survivorship care process. It is the development of this document that provides the young person with the information that they need to self-manage the next phase of their psychosocial recovery and manage their own future. The details obtained in the screening tool, including the future goals, must be sufficiently addressed to enable the young person to move forward with their life. It is important that the survivor feels that they have the support and information they need to facilitate the best outcome. Thus, the care plan provides a framework to promote self-management by the young person and communication between professionals.

While it is always best practice to identify needs in a holistic manner, it is important to remember that some of the issues identified in the screening tool may have been part of the young person's life prior to their diagnosis. It is not the role of the *AYA Psychosocial Survivorship Care Process* to address all of the underlying issues. Rather, it is important that all issues impacting the life of the young person that can be linked to the cancer experience are identified and addressed as part of the care plan in a manner that allows the survivor to move forward with their life.

Administration Guidelines

The *AYA Psychosocial Survivorship Care Plan* outlines what happens next for the young person by turning the issues highlighted in the screening tool into action points. It can be developed as part of the screening tool process or as a separate consultation – depending upon the practices of the treating team. A quiet setting is required to develop the care plan and it is anticipated that it will take between 45 to 60 minutes. An important part of this process is having access to appropriate information to meet the varying needs of this survivor group and understanding what resources are available for support and referral. The development of an information database and local referral directory is essential to this process.

Insert goals identified (Step One)

To ensure that the care planning is focused on the achievement of future goals, as well as addressing areas of concern, it is recommended that the goals identified are recorded on the top of the care plan and are referenced throughout the care planning process. The goal of the *AYA Psychosocial Survivorship Care Plan* is to meet the needs of the young person by assisting them to return to a 'normal' life. To achieve this, planning should be positive and future focused.

While there is space for a number of different identified goals, it is not essential that they are all filled out – rather, it is recommended that the young person is able to identify a minimum of three things that they are working towards. If they are unable to do so, it is important that the clinician administering the measure is able to support them to 'break down' what they want to achieve into manageable, and multiple, steps.

Insert Items of Distress (Step Two)

Items that have been identified by the patient on the screening tool as contributing to current distress levels should be indicated on the Issue List. These items become the working list for the care plan. As is standard practice, if there are too many items specified on the screening tool the survivor should indicate which issues are of the greatest importance. In line with the collaborative approach of the *AYA Psychosocial Survivorship Care Process*, it is important that the young person identifies the most pressing issues, rather than relying on the clinical judgement of the clinician. These should form the basis of the development of the initial *AYA Psychosocial Survivorship Care Plan*.

Code Items (Step Three)

Once rated, a discussion must be had regarding the next steps in addressing the issues identified. To assist with clarity (and data collection for research), a coding system can be employed to simplify the process and enhance understanding for the young person. The coding system covers the basic clinical responses to indicators of need; R = referral, I = Information provision, ATM = AYA team management. The responses identified by the clinician and the reasons behind each response, should be discussed and explained to the patient during this process.

1	**Referral** Indicates that there is an identified individual (for example, GP, school counsellor or private physiotherapist) or group (for example, CanTeen, Leukaemia Foundation or Cancer Council) that would be best placed to manage the issue. The clinician will either make a referral or provide referral details, depending upon the most appropriate process.
2	**Information provision.** Indicates that the issue identified is predominantly due to a lack of appropriate information. It is anticipated that the provision of relevant information will address this identified need. Issues that may be addressed through the provision of information include those identified within the tick box section (for example, long-term follow-up, familial cancer, fertility options or healthy living).
3	**AYA team management.** Indicates that the issue identified is routinely addressed as part of standard survivorship management and will be addressed by a member of the treating team (for example, facilitating the access to entitlements from CentreLink or building relationships between the survivor and their school to assist with education). ATM is not an ongoing solution. It is recommended that, once the immediate issue is addressed, the ongoing management is best dealt with through a referral or information provision. This is in keeping with the self-management approach of the survivorship process.

Develop Plan (Step Four)

To enable the self-management of the survivorship plan, it is essential that the steps involved in addressing the issues identified and the future goals are clearly and explicitly explained to the young person. It is imperative that they are aware of the steps suggested to manage each of the issues and what their role is in making this happen. While this should be a collaborative process, it must also be recognised that the survivor does not necessarily have the knowledge of available information and supports they require. They must receive this from the clinician in order to be able to move forward with managing their own recovery.

Referral Details (Step Five)

The names and contact details of all referrals should be listed on the *AYA Psychosocial Survivorship Care Plan*. Once identified, it is recommended that any referrals are made within 48 hours. All relevant details for referrals should be kept within easy access so that they can be provided to the survivor during the care planning session. Once these referrals are made, or information is provided, it is then anticipated that the young person is able to manage subsequent contact and appointments. However, it should be made clear that the young person can contact the clinician who developed their survivorship care plan with any follow-up questions or concerns.

Signatures (Step Six)

There is a signature section at the bottom of the *AYA Psychosocial Survivorship Care Plan* that requires both lead clinician and the patient to complete to highlight their understanding of the outcomes of the care plan and the next steps identified. However, to encourage communication between the lead clinician and the young person's GP, an additional signature space has been provided. This signature space should be completed by the GP once they feel they have all of the relevant information they require to be fully involved in supporting the psychosocial survivorship journey of the young person.

A review of the *AYA Psychosocial Survivorship Care Plan* Reviews should occur at approximately six months and twelve moths post-treatment completion, at significant time points or as requested throughout the survivorship journey. It is the combined responsibility of the survivor, lead clinician and GP to anticipate and identify when these reviews should occur.

AYA Oncology Lead Sites

New South Wales and Australian Capital Territory

NSW/ACT Youth Cancer Service

Email: sydneyAYACS@sesiahs.health.nsw.gov.au
Phone: 02 9382 0945
Mobile: 0400 474 691 (business hours)

Queensland

QLD Youth Cancer Service

Email: QYCS_CHQ@health.qld.gov.au
Phone: 07 3068 3745
Mobile: 0427 904 214

South Australia and Northern Territory

SA/NT Youth Cancer Service

Email: youthcancer@health.sa.gov.au
Phone:08 8222 2804
Mobile: 0407 573 431
Fax: 08 8222 0740

Victoria and Tasmania

VIC/TAS Youth Cancer Service

Email: ontrac@petermac.org
Phone: 03 9659 1744
Fax: 03 9656 1192

Western Australia

WA Youth Cancer Service

Email: ayaccs@health.wa.gov.au
Phone: 08 6383 3416
Mobile: 0400 021 874
Fax: 08 6383 3450

Clinical Contributors

Project Steering Committee

Name	Title	Institution
Susan Palmer	Psychologist/Researcher	Private Consultant
Michael Osborn	Haematologist	Youth Cancer Service SA/NT, Royal Adelaide Hospital and Women's and Children's Hospital

Clinician Working Party

Name	Title	Institution
Cath O'Dwyer	Clinical Nurse Consultant	Adolescent & Young Adult Cancer Service (AYACS), Sydney Children's/Prince of Wales Hospitals, New South Wales
Michael Hopkins	Social Worker	Adolescent and Young Adult Cancer Service (AYACS) Prince of Wales Hospital New South Wales
Fiona Maguire	Clinical Nurse Consultant	Adolescent & Young Adult Cancer Service (AYACS), Sydney Children's/Prince of Wales Hospitals, New South Wales
Emma Sayers	Projects team	Wellness and Supportive Care, Cancer Services, Austin Health, Victoria
Kate Thompson	Manager, onTrac@PeterMac	Victorian Adolescent & Young Adult Cancer Service Peter MacCallum Cancer Centre, Victoria
Esther Yeoman	Nurse Coordinator, onTrac@PeterMac	Victorian Adolescent & Young Adult Cancer Service Peter MacCallum Cancer Centre, Victoria
Priscilla Gates	Liasion Nurse - Survivorship Care Planning Implementation Project	Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, Victoria
Danielle Tindle	Senior Project Officer	Queensland Adolescent and Young Adult Cancer Services, Royal Children's Hospital, Queensland
Aaron Thompson	Former Clinical Nurse Consultant	After Cancer Therapy Service, Queensland Children's Cancer Centre, Queensland
Marianne Fenton	CNC Transitional Care Project Officer	Royal Children's Hospital, Queensland

Name	Title	Institution
Belinda Matigian	Senior Social Worker	Adolescent and Young Adult Oncology, Department of Social Work, Princess Alexandra Hospital Health Service District, Queensland
Gillian Myles	Former Clinical Nurse Consultant	Adolescents and Young Adults, Princess Alexandra Hospital Health Service District, Queensland
Olivia Urbaniec	Clinical Psychologist	Youth Cancer Service SA/NT, Royal Adelaide Hospital and Women's and Children's Hospital, South Australia
Sharon Bowering	Fmr Cancer Care Coordinator	Youth Cancer Service SA/NT, Royal Adelaide Hospital and Women's and Children's Hospital, South Australia
Michael Osborn	Haematologist/Oncologist	Youth Cancer Service SA/NT, Royal Adelaide Hospital and Women's and Children's Hospital, South Australia
Anne Gannoni	Department of Psychological Medicine	Women's and Children's Health Network, South Australia
Gordon Miles	Psychologist	Princess Margaret Hospital for Children, Western Australia
Kendall Stratton	Cancer Nurse Specialist	Adolescent and Young Adult, WA Cancer & Palliative Care Network, Department of Health, Western Australia
Orietta Simons	Youth Worker	Adolescent and Young Adult, WA Cancer & Palliative Care Network, Department of Health, Western Australia
Janine Deevy	Adolescent and Young Adult Cancer Care Coordinator	Royal Brisbane and Women's Hospital, Queensland
Michele Blohm	Divisional Manager	ACT and Southern NSW, CanTeen, Australian Capital Territory
Lyndal Gray	Senior Leisure Therapist	Adolescent & Young Adult Oncology, Occupational Therapy Department, Princess Alexandra Hospital, Queensland

Patient Working Party

Name			
Lucy Lysenko	**Jessie Macallan**	**Casey MacKay**	**Anders Wong**

References

CanTeen. (2011). *Adolescent and Young Adult Oncology Psychosocial Care Manual*. Australia: CanTeen

National Comprehensive Cancer Network (NCCN). (2011). *NCCN Clinical Practice Guidelines on Oncology for Distress Management: V.I.2011.* Available at http://www.nccn.org

DH, MacMillan Cancer Support and NHS Improvement. (2010). *The National Cancer Survivorship Initiative Vision (NCSI).* United Kingdom: Department of Health. Available at http://www.ncsi.org.uk

Horowitz, M., Fordis, M., Krause, S., McKellar, K. and Poplack, D. (2009). *Passport for care: Implementing the survivorship care plan.* Journal of Oncology Practice, 5(3), 110-112.

LiveStrong. (2010). *How cancer has affe cted post-treatment survivors: A LiveStong report.* Available at http://www.livestrong.org/pdfs/3-0/LSSurvivorSurveyReport

Palmer, S. and Thomas, D. (2008). *A practice framework for working with 15-25 year old cancer patients treated within the adult health sector.* Melbourne: onTrac@PeterMac. Available at http://www.petermac.org/ontrac/professional.asp#pracframe

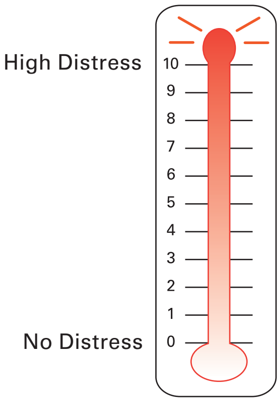
Appendices

- AYA Oncology Psychosocial Survivorship Screening Tool
- AYA Oncology Psychosocial Survivorship Care Plan

Adolescent and Young Adult Oncology Psychosocial Survivorship Screening Tool

1. General Distress

How much distress have you been feeling over the past week? (Circle a number from 0 to 10)



Distress Thermometer reproduced and adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines TM) for Distress Management V.1 2011 © 2010 National Comprehensive Cancer Network, Inc. All rights reserved.

Office Use Only:	
Survivor Name	
Date of Administration	

2. Specific Areas of Concern or Adjustment?

In the boxes provided, please indicate (✔) which areas have been an issue for you over the past month.

Physical

☐ General appearance
☐ Eating or appetite
☐ Constipation or diarrhoea
☐ Sexual concerns
☐ Pain
☐ Adjusting to new disability
☐ Less energy than before cancer
☐ Less capacity to do 'normal' activities
☐ Unable to exercise like used to
☐ Feeling weak
☐ Problems with sleeping
☐ Side effects from treatment

Emotional

☐ Sadness
☐ Feeling alone or isolated
☐ Anxiety
☐ Boredom
☐ Anger or frustration
☐ Extreme moodiness
☐ Feeling that everything is an effort
☐ Feeling hopeless or helpless
☐ Feeling confused
☐ Feeling that life is not worth living
☐ Thoughts about suicide or harming self

Social

☐ Feeling isolated from friends
☐ Not wanting/able to do 'normal stuff' with friends
☐ Friends don't understand
☐ Feeling different from friends
☐ Not wanting/able to meet new people
☐ Worry about boyfriend/girlfriend/partner
☐ Relationship breakdown (boyfriend/girlfriend/partner)

Concentration

☐ Short attention span or concentration
☐ Trouble remembering things
☐ Feeling like living in a 'fog'
☐ Taking longer to finish things than before

Fertility

☐ Not knowing fertility status / options
☐ Cost of fertility treatment
☐ Discussing fertility with others
☐ Grief over fertility

Impact of experience

☐ Loss of secure future
☐ Change in identity
☐ Loss of meaning or purpose
☐ Loss of financial independence
☐ Challenge to faith or spirituality
☐ Sadness over death of other patients
☐ Guilt over death of other patients (Survivor Guilt)
☐ Feeling responsibility to have a 'meaningful' life

Family

☐ Feeling family don't understand
☐ Lack of support from family
☐ Feeling responsibility to 'protect' family from truth
☐ Worry about impact cancer has had on family
☐ Worry about family members

Lifestyle

☐ Smoking cigarettes
☐ Drinking alcohol
☐ Drug use
☐ Concerns about sex / unprotected sex
☐ Living an unhealthy lifestyle
☐ Not attending appointments (medical or other)
☐ Doing other things that put life at risk

Survivorship

☐ Not wanting to tell others about having cancer
☐ Hiding 'real' feelings from others
☐ Playing 'catch up' with achievements of friends

☐ Feeling like missed out on life because of cancer
☐ Accepting changed circumstances due to cancer
☐ Worry about family/friends getting cancer
☐ Worry about family having 'cancer gene'
☐ Worry about long- term effects of treatment
☐ Worry about cancer coming back
☐ Worrying thoughts about death or dying

Employment

☐ Getting a job
☐ Returning to work
☐ Support from employer
☐ Employment discrimination
☐ Change in career aspirations

Education

☐ Returning to school/university/ TAFE
☐ Catching up on class work
☐ Concern about your rights / responsibilities

Other areas of concern

____
____
____
____
____
____

What are your goals for the future?

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________

3. Please indicate (✓) what further information you would find helpful:

Your cancer type	☐	Long term follow-up	☐	Education support	☐
Treatment received	☐	Financial support	☐	Employment assistance	☐
Psychosocial support	☐	Fertility support	☐	Ways to improve health	☐
Support groups	☐	Familial cancer	☐	Leisure activities	☐

I, ______________________________ understand that the above information will be used by my treating team develop my personalised survivorship care plan.
(Patient's name)

Patient Signature: ______________________________ Date: ______________

Clinician Signature: ______________________________ Date: ______________

YOUTH CANCER SERVICE | canteen

Adolescent and Young Adult Oncology Psychosocial Survivorship Care Plan

Office Use Only:			
Survivor Name		DT Score	
Date of Administration		Lead Clinician	

Future goals identified:

1.	3.	5.
2.	4.	6.

Information provided or required:

Your cancer type		Long term follow-up		Education support	
Treatment received		Financial support		Employment assistance	
Psychosocial support		Fertility support		Ways to improve health	
Support groups		Familial cancer		Leisure activities	

Intervention codes: **R**: referral **I**: information provision **ATM**: AYA team management

Issue (cross out those not indicated)	**Code**	**Plan** (what to do, who to do it, follow up required)	**Referral Details** (name, number, referral date)
Physical			
Emotional			
Concentration			
Fertility			
Impact of Experience			

Issue (cross out those not indicated)	**Code**	**Plan** (what to do, who to do it, follow up required)	**Referral Details** (name, number, referral date)
Family			
Social			
Lifestyle			
Survivorship			
Employment			
Education			
Other areas of concern			

I, ______________________________ understand that the above information may be used by my treating team to communicate with other professionals about my survivorship care.
(survivor insert name)

Survivor Signature: ______________________________ Date: __________

Clinician Signature: ______________________________ Date: __________

GP Signature: ______________________________ Date: __________

Together we will improve outcomes for young people with cancer, boosting survival and improving their quality of life.

www.youthcancer.com.au

YOUTH CANCER SERVICE | canteen