

Adolescent and Young Adult Oncology Psychosocial Care Manual



An evidence-based practice guide to the psychosocial management and care of adolescents and young adults with cancer during treatment.

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Foreword

The need to provide age appropriate health care for adolescents and young adults in Australia is great. To address this need Canteen, in partnership with Cancer Australia, developed the National Service Delivery Framework for Adolescents and Young Adults with Cancer (NSDF) during 2007-2008. The aim of this framework is to maximise survival and quality of life outcomes for young people affected by cancer, and to enhance supportive care services for them and their families. An updated Framework, renamed the National Youth Cancer Framework is being developed and will be available from mid 2016.

The Australian Government, in recognition of this need, provided Canteen with \$15million for delivery of the *Youth Cancer Networks Program* (YCNP) from 2009 to 2012, with a further \$17.88million commitment from 2013 to 2017. This program consists of national initiatives such as research and data collection and the delivery of Youth Cancer Services in five jurisdictions, which provide medical treatment and psychosocial support for young people diagnosed with cancer. The Adolescent and Young Adult Oncology Psychosocial Care Manual was developed in 2011

as an important guideline for health professionals supporting young people with cancer.

This manual embodies best practice in psychosocial screening, assessment, and care plan development. It represents an important tool for the provision of age appropriate supportive care that every young person with cancer has the right to receive. In recognition that psychosocial concerns don't cease when treatment ends, the SA/NT YCS has developed a partner manual, the Adolescent and Young Adult Oncology Survivorship Care Manual. Together, the two psychosocial manuals provide a clearly articulated pathway for provision of psychosocial support across the cancer care continuum.



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Contents

Foreword and Acknowledgements	i
Contents	ii
Psychosocial Assessment and Care of AYA Patients	1
Psychosocial Needs of AYA Patients	1
Development of Care Process and Psychosocial Tools	2
Adolescent and Young Adult Psychosocial Care Process	2
Minimum Standard of Care	2
Recommended Skill Level for Administration	3
Assumed Knowledge Base for Administration	3
Noted Exclusions	4
Care Pathway	5
Initial Psychosocial Screen	5
Development of Care Plan	5
Psychosocial Assessment / Second Screen	5
Development of Working Care Plan	5
Progress Screen and Care Plan	5
Screening Tool	7
Administration Guidelines and Clinical Recommendations	7
Distress Thermometer (Step One)	7
Needs Assessment (Step Two)	9
Information Provision (Step Three)	10
Care Plan Appointment (Step Four)	12
Signatures (Step Five)	12
Care Plan	13
Administration Guidelines and Clinical Recommendations	13
Rate Items (Step One)	13
Code Items (Step Two)	15
Develop Plan (Step Three)	15
Referral Details (Step Four)	16
Lead Clinician (Step Five)	16
Date for Review (Step Six)	16
Signatures (Step Seven)	16

Psychosocial Assessment Measure	17
Administration Guidelines and Clinical Recommendations	17
Goal of Assessment	19
Confidentiality	19
Detailed History of Cancer Experience	19
Physical Systems Review	19
Family History (Home)	20
Education	20
Employment	21
Social History (Activities)	21
Habits (Drugs and Alcohol)	21
Relationship and Dating History (Sexuality)	22
Religious or Spiritual Beliefs	22
Mental Health Status (Suicide/Depression)	22
Current Stressors	23
Strengths and Supports	23
Additional Comments	24
Areas to Address	24
Signatures	24
Revise Care Plan	24
Youth Cancer Services	25
Contributors	26
Project Steering Committee	26
Clinician Working Party	26
Clinical Reviewers	27
Patient Working Party	29
References	29
Appendices	30
Adolescent and Young Adult Psycho-Oncology Screening Tool (AYA-POST)	
Adolescent and Young Adult Psycho-Oncology Care Plan	
Adolescent and Young Adult Psycho-Oncology Assessment Measure	

Psychosocial Assessment and Care of AYA Patients

Age based screening tools and assessment measures are crucial to the provision of best practice care for Adolescent and Young Adult (AYA) cancer patients. Unfortunately, there are limited psychosocial tools developed for this age group and paediatric or adult measures are often distributed with the assumption that they are 'close enough'.

This manual and the accompanying tools strive to improve what currently exists. While using as their foundation many of the best available measures (including the National Comprehensive Cancer Network (2011) Distress Thermometer, and the Goldenring and Cohen (1988) HEADSS Assessment), the tools have been developed in consultation with (a) Australia's leading AYA clinicians, (b) young people currently undergoing therapy, and (c) a group of AYA survivors. The result is the first available AYA specific Screening Tool, Care Plan proforma, and Psychosocial Assessment Measure developed for use within the oncology sector. This Manual is accompanied by the Adolescent and Young Adult Oncology Psychosocial Survivorship Care Manual (2012/2022). This separate survivorship manual outlines the process for AYA patients who have completed treatment.

These new tools will assist clinicians working with this population group to support psychosocial coping during active treatment and promote healthy post-treatment survivorship. The AYA specific Screening Tool is called the Adolescent and Young Adult Psycho-Oncology Screening Tool (AYA-POST) and has been validated with an international sample of recently diagnosed AYAs (Patterson et al., 2021). Further validation procedures will add to the veracity of the other tools over time (Patterson et al., 2015). They highlight a clinically-recognised minimum standard of care that all young patients, regardless of treatment location, have the right to receive.

It should be noted that although this manual offers detailed guidance for administering the screening and assessment measures and developing a care plan, there is no substitute for applied training. We strongly recommend that before you use this manual, you participate in appropriate training. Contact your local Youth Cancer Service for more details. (*Refer also to sections in this manual on Recommended Skill Level and Assumed Knowledge Base for Administration*).

Psychosocial Needs of AYA Patients

The psychosocial support needs of adolescent and young adult patients are different from patients of other ages. Their developmental stage has them straddling emerging adulthood and adolescence. Their cognitive, emotional and social skills are under development while their desire for independence and separation from parents is increasing. This combination can create a challenging environment for the clinician as they tread the fine line between meeting the needs of the patient and keeping family members informed of the process.

The clinician working with these patients has a dual role; firstly, they are there to support the AYA patients and meet the immediate needs associated with a cancer diagnosis and its treatment. Secondly, they

must facilitate the healthy psychosocial development and survivorship of the patient.

A preventative approach, comprising regular psychosocial screening and care planning, enables treating teams to identify those patients at risk of a negative psychosocial outcome, monitor the progressive coping of the patient, and identify areas of need requiring additional care and support. This approach ensures that young people receive the support they need, even as their needs change.

This manual, and the accompanying psychosocial tools, promote best practice care for this age group by recognising and addressing age specific needs. Incorporated within this document are recommendations that address appropriate age-based support, information, and clinical care needs.

Development of Care Process and Psychosocial Tools

The care process and accompanying psychosocial tools presented in this manual were developed in conjunction with a group of AYA patients and Australia’s leading AYA nursing and psychosocial clinicians. The patient perspective was represented by a number of patients undergoing active treatment and a group of young cancer survivors. These young people, aged between 16 and 24 years, were treated in a range of institutions (paediatric and adult; private and public) for a range of diagnoses (including Hodgkin’s Lymphoma, Ewing’s Sarcoma, Testicular Cancer and Acute Lymphoblastic Leukaemia). The clinical perspective was represented by a group of ten specialist AYA clinicians. These clinicians represented each of the lead AYA oncology treatment sites at the time from Victoria, New South Wales, Queensland, South Australia and Western Australia and included experts in the fields of nursing, social work, psychology, and paediatric oncology. Through the ongoing consultation and revision by these patient and clinical working groups, the AYA Care Process and Psychosocial Tools were developed.

Adolescent and Young Adult Psychosocial Care Process

The AYA Care Process is based upon a three step psychosocial care pathway that integrates AYA-POST, Care Plan and Assessment Measure (see Figure 1.). Developed to be administered at key time points during the patient journey, the combined care pathway aims to

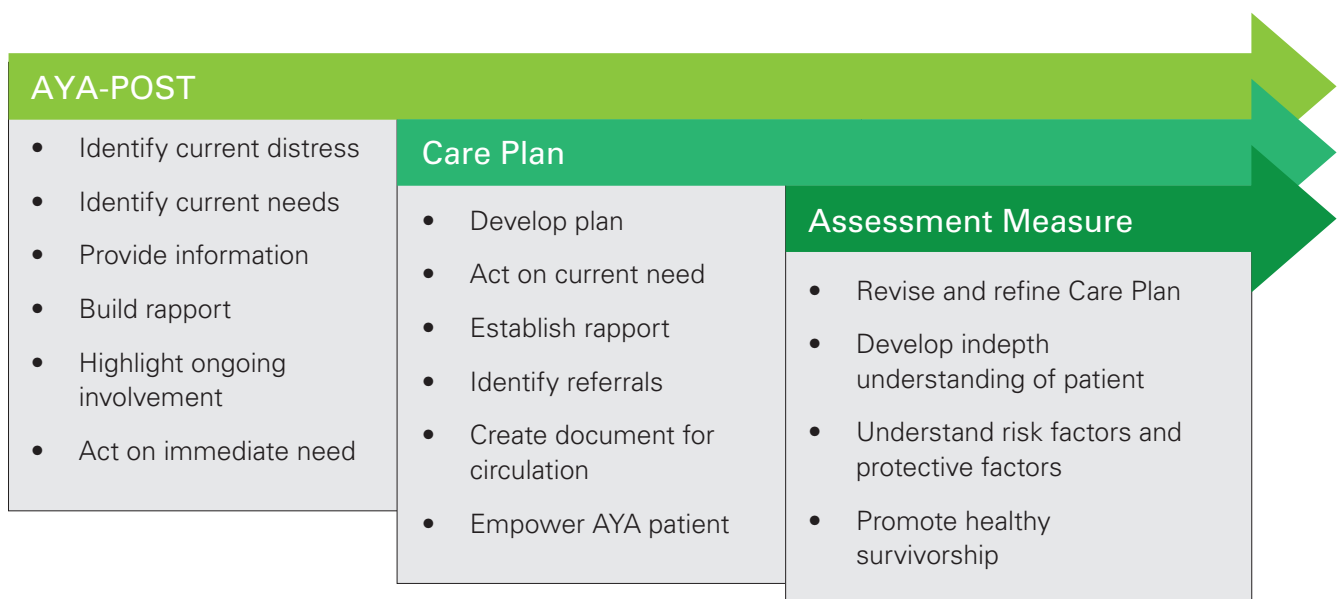
support the young person throughout their treatment by addressing current support needs, and takes into consideration needs that may be most significant post-treatment for healthy survivorship. Each step in the process has a specific role in the provision of optimal care and, while there is some flexibility in timelines, it is recommended that the care process is administered in the manner intended.

The desired outcome of the three-step psychosocial care pathway is the development of individual Care Plans for each AYA patient. These Care Plans are to be flexible and adaptable. They focus on the young person and their current supportive care needs, but also address their survivorship goals and aspirations.

Minimum Standard of Care

At a minimum, it is recommended that administration of the AYA-POST occurs at: (a) diagnosis, (b) early treatment, (c) six months post-diagnosis, and (d) treatment completion. Resources permitting, a full psychosocial assessment is recommended during the care-planning phase and at regular intervals throughout the cancer journey. Furthermore, in order to support the outcomes of the tools, each young patient should have access to specialist age appropriate psychological support. Treatment centres without ready access to such services are encouraged to develop a referral directory of appropriately trained mental health professionals in the community.

Figure 1. The AYA psychosocial care pathway



Recommended Skill Level for Administration

It is recommended that clinicians administering the AYA-POST and Care Plan have as a minimum, a degree in nursing, psychology, or social work. Specialist interest in AYA health and communication skills training are an advantage.

Further specialist training, and consultation with your local Youth Cancer Service, is recommended for clinicians administering the Assessment Measure. All clinicians managing the care pathway of AYA patients are encouraged to regularly connect with the Youth Cancer Service for support and guidance (contact details for each state can be found at the back of the manual).

Assumed Knowledge Base for Administration

Working with AYA patients may require a tailoring of normal clinical practice in order to meet the developmental needs of patients. Four areas of clinical practice that may need to be adapted to ensure the provision of best-practice care for this age group are; (a) communication, (b) confidentiality, (c) engaging the patient, and (d) a family systems management approach. It is assumed that those administering the enclosed Psychosocial tools are familiar with these practice areas.

Clinicians looking for further education or training regarding the management of a young person should contact an AYA cancer service in their state. Details can be found at the back of this manual.

Communication

AYA patients may struggle to understand many of the complex concepts associated with diagnosis and treatment. This may be due to (a) the language used, (b) the communication style of the clinician, (c) the intimidating environment, (d) the cognitive development of the patient, or (e) a combination of these factors. Whatever the underlying reason, many clinicians will need to actively change their communication style when working with AYA patients.

Confidentiality

Respecting and maintaining confidentiality is an essential component of best practice AYA care.

Young people may be engaged in activities or experiencing situations, such as exploratory sexual activities, experimenting with alcohol and illicit substances, emerging mental health problems, and unsatisfactory parental relationships, that place them at risk or may compromise their treatment. Some young people may not speak openly and honestly about their fears or concerns with parents or partners present as they may wish to protect them from further upset or may not wish to disclose activities that they are aware will be frowned upon.

Engaging Young People

Young people can be notoriously difficult to engage in a clinical setting. This is particularly the case when they feel angry, scared and intimidated – all of which are common emotions during the early stages of a cancer diagnosis and cancer treatment. While there are no guaranteed ways to engage with a young patient, addressing the issues of confidentiality and privacy, talking directly to the patient in a clear and easy to understand language, taking your time, encouraging questions, and highlighting the collaborative nature of the relationship will all assist. Furthermore, young people respond well to firm boundaries. It provides a sense of safety and promotes trust.

Family Systems Approach

Throughout the process of managing AYA patients it is important to recognise the significance of familial issues. Many AYA patients remain embedded within the family system, or will return to the family during their treatment. Familial issues should be considered when developing the Care Plan, as should the needs of any partners involved. If, during the completion of the Care Plan, the patient identifies stress associated with the family management of the illness, support and information should be provided to relevant family members.

Noted Exclusions

The psychosocial management of AYA patients is a very broad area. To ensure the document is manageable and representative of a large proportion of patients, some essential areas of care were excluded.

The areas of AYA survivorship and palliative care have not been addressed in this document. This should not be interpreted as an indication that these aspects of psychosocial care are not important – rather, they were thought to be too important to be added as an adjunct to the standard care pathway. As was indicated earlier, a separate manual has been developed that outlines the care process for AYA patients in the survivorship phase.

In a similar vein, the specific needs of family members (including AYA siblings of patients) have not been addressed in detail within this document. Once again, while the psychosocial issues and support needs of family members are viewed as central to the healthy psychosocial functioning of the AYA patient, there was not the scope to address these issues appropriately in this document.

Finally, these tools, while they have been developed to improve the quality of AYA patient management and psychosocial care, are designed to be implemented as part of a wholistic multidisciplinary approach to AYA patient management. They are not the only factor in providing best practice care. They are not to be used as a substitute for clinical judgment or multidisciplinary team planning. Furthermore, the recommendations highlighted within should not be used as a substitute for existing institutional policies and procedures.

Care Pathway

The development of the care pathway was informed by clinicians and patients. The times determined for administering the instruments, and the frequency with which this occurred, are intended to correspond with the availability of clinical resources and the needs of the patients throughout their cancer journey. The pathway presented herein represents a minimum standard of care for all AYA patients.

Initial Psychosocial Screen

Every young person should receive a psychosocial screen within two weeks of diagnosis and/or first treatment cycle. The AYA-POST identifies the level of distress currently experienced by the patient and the nature of such distress. As patients can be sensitive to the implications of psychosocial screening, the administration of the AYA-POST should be accompanied by educational information that normalises psychosocial management in the context of wholistic care provision. This information should be provided to the patient, parents and significant others.

Development of Care Plan

Within two weeks following the administration of the AYA-POST, a Care Plan based on the outcomes of the AYA-POST should be developed by the treating team in collaboration with the patient. The Care Plan focuses on addressing the current needs of the patient through referral, information provision, further assessment, and/or standard patient management. With the consent of the patient, the Care Plan becomes the central document for wider circulation to other professionals involved in the care of the young person including general practitioners (GPs), community palliative care teams, regional share care teams, community mental health teams, surgical teams external to the primary treatment site, and other treatment sites.

Psychosocial Assessment / Second Screen

Six to eight weeks post diagnosis and/or treatment commencement is a significant period for the patient. It is often a time of changing and/or increasing need. Resources permitting, it is beneficial for all young people to receive a full psychosocial assessment during this stage of their cancer journey to further inform care planning and the provision of psychosocial support. If resources are not sufficient

to conduct the psychosocial assessment, a second AYA-POST should be administered at this time to identify any changes in need from the patient. Again, the 'Working Care Plan' should be completed within the following two weeks with the involvement of the young person.

Development of Working Care Plan

While the template for the Working Care Plan is the same as that used for the initial Care Plan, the information documented differs due to (a) the increased knowledge the clinician has of the patient, their family and their environment, and (b) the benefits associated with the assumed improvement in relationship between patient and clinician that occurs over time. The Working Care Plan should have further depth of detail than the initial Care Plan and incorporate patient-specific strategies to manage adherence, identify risks and plan for survivorship.

Progress Screen and Care Plan

Six months post diagnosis and/or treatment commencement is another significant period for the patient. It is recommended that all AYA patients complete a 'Progress Screen' at this stage. Any changes in need should then be incorporated into a revised Care Plan to support the patient as they move forward.

Any further screening should take place at the clinician's discretion or the patient's request. At a minimum, this should occur at remission, recurrence, or progression. However, additional time points to consider include; (a) changes in treatment, (b) changes in treatment goals, (c) treatment completion, (d) during significant times in the young person's life (for example; moving into a new school year, relationship break-ups, commencement of summer holidays, family break-down).

Figure 2. Care Pathway

First Screen (~ at diagnosis)	Given to patient at earliest occasion.
Initial Care Plan (~ 2 weeks post diagnosis)	Developed in consultation with patient at earliest occasion post screen completion. Care Plan developed to support patient as they commence treatment.
Second Screen and Assessment (~ 6 to 8 weeks)	Completed once treatment is established. Resources permitting, a full assessment should be conducted at this time.
Working Care Plan (~ 8 to 10 weeks)	Developed with detailed knowledge of patient, their family and environment. Includes strategies to manage adherence, identify risks and plan for survivorship.
Progress Screen (~ 6 months and as required)	Conducted to address any changes in patient experience, illness trajectory, family or environment throughout the cancer journey.
Revision of Working Care Plan (~ 6 months and as required)	Plan revised accordingly to remain relevant and effective.

Screening Tool

The Adolescent and Young Adult Psycho-Oncology Screening Tool (AYA-POST) has five steps designed to meet the support needs of the age group and promote a collaborative patient-clinician relationship. These five steps are; (a) the distress thermometer, (b) the check list of 'areas of concern', (c) the tick box for information provision, (d) the appointment date for the Care Plan development, (e) the signatures, and (f) a tick box for trial participation.

Aside from building trust and information provision, the primary goal of the Adolescent and Young Adult Psycho-Oncology Screening Tool (AYA-POST) is to identify the levels of distress currently experienced by the young person and to ascertain what the issues are that are contributing to the distress levels. In this setting, distress is defined as "a multifactoral unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment." (National Comprehensive Cancer Network; NCCN, 2011).

Administration Guidelines and Clinical Recommendations

The AYA-POST is to be administered to all young people as close to diagnosis as possible. The information gained from the assessment will facilitate treatment commencement and patient coping during the early stages of their patient journey – thus, timely administration of the measure is essential.

How the measure is administered (for example, in a patient waiting room, in the clinical setting, over the phone, or as a mail-out) is to be determined by the individual treating teams and commensurate with available resources. At this stage, the focus should be on the completion of the measure. The environment in which this occurs can be flexible.

The AYA team member administering the AYA-POST must attempt to distinguish between normal levels of distress that are managed through standard procedures and levels of distress that exceed what is considered normal and require immediate intervention. Adding to the complexity of this task in the context of AYA patient management is the need to consider AYA distress within developmentally appropriate parameters. Often withdrawal, quietness, and irritability in young people undergoing cancer treatment represent normal AYA behaviours in the context of their disease. Therefore, while the distress thermometer and the needs assessment are useful in supporting the clinician to address patient need, they serve as a guide only. The information presented below is not to be used as a substitute for the judgment of an experienced psychosocial clinician.

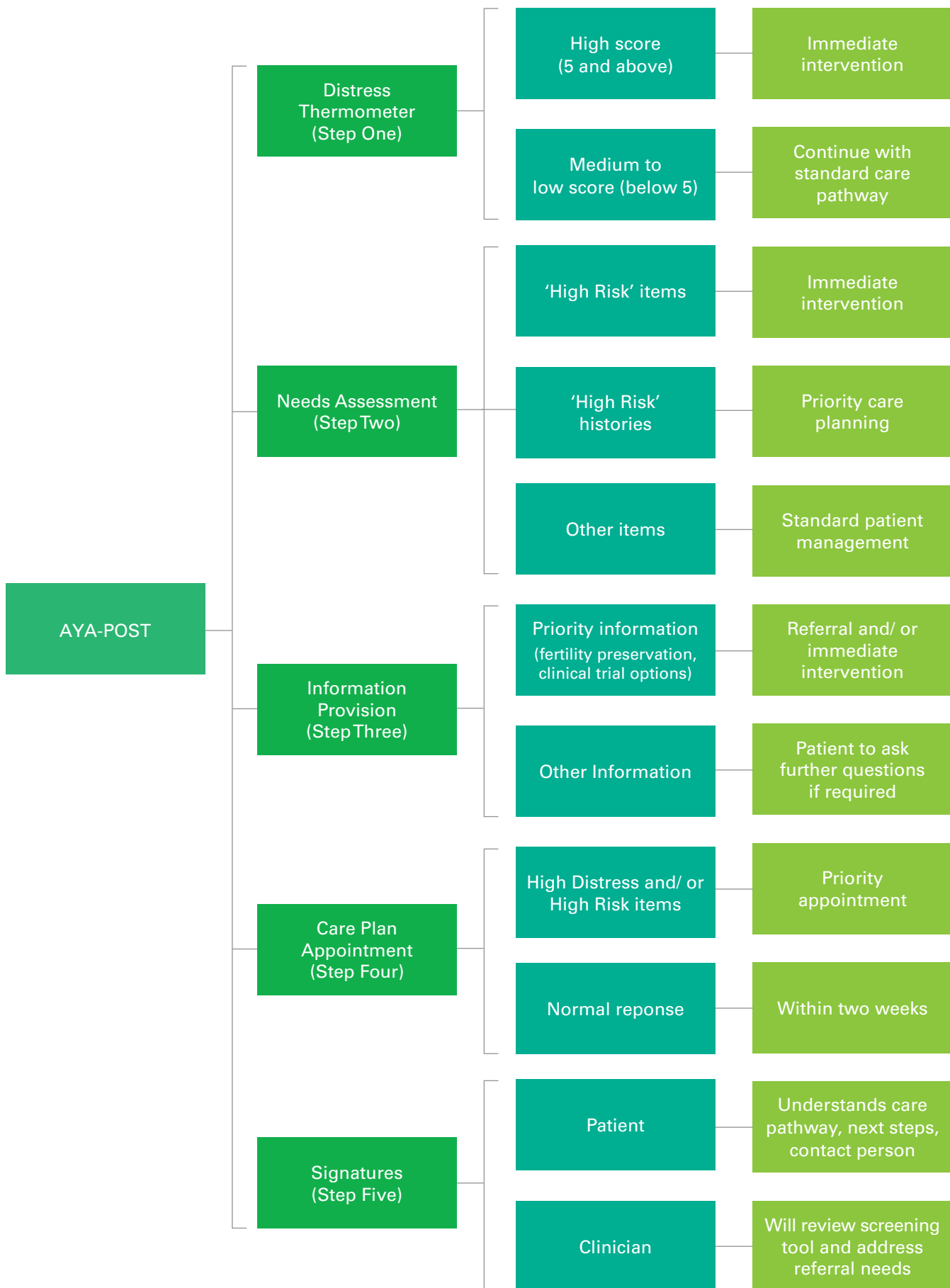
Given the vulnerable nature of the AYA population group, it is always best to err on the side of caution when developing psychosocial Care Plans or providing supportive care. Clinicians managing young people outside of an AYA site should consider contacting the AYA site in their State for further support and guidance or for consolidation of impressions and plans.

As part of the screening process, the NCCN (2011) recommend that the treating team should advise all patients that they may experience greater than usual levels of distress at some points in the treatment and during the course of the illness. It is paramount that patients understand, and feel comfortable, telling their key worker (or other treating team member) if they feel a higher level of distress than usual so that the team can evaluate their distress and facilitate the appropriate assistance. While the preventative management of the AYA patient recommends regular screening of the patient, the patient must also recognise their role in managing their care. This should be made clear to the patient during each administration of the AYA-POST.

Distress Thermometer (Step One)

The distress thermometer is an objective measure of patient distress. It asks the simple 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)?" Not only does this give the patient an opportunity to respond to the question, but it normalises distress as a common

Figure 3. Screening Tool Flow Chart



part of the cancer experience and presents the opportunity for the patient to raise the topic further with their treating team.

It is important to recognise that a cancer diagnosis is likely to cause levels of distress in almost all patients. 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. The recommendations below are based on an international validation study of the distress thermometer with AYAs which confirmed that a cut-off score of 5 is the most appropriate clinical cut-off for recently diagnosed AYAs (Patterson et al., 2021).

Recommendation.

Scores less than 5 = Mild Distress

Adult research indicates that 'mild distress', as represented by a score of less than four on the distress thermometer, characterises what could be termed an 'expected' level of distress given the circumstances and form part of the normal response to a cancer diagnosis and its treatment. Standard patient management is recommended.

Recommendation.

Scores of 5 or more = Significant Distress

Scores of 5 or more, which occur in 25% to 48% of AYAs, indicate a significant level of distress that requires further evaluation (Patterson et al., 2021). The score should be viewed as a trigger for timely action. What the action should be, and the immediacy of the response, is determined by having the patient complete section two of the AYA-POST (Specific Areas of Need or Concern). These results will then form the foundation for the development of a management plan.

Needs Assessment (Step Two)

The needs assessment section of the AYA-POST (titled Specific Areas of Need or Concern) identifies six specific areas of concern and includes a section to highlight any worries or concerns not identified in the checklist. The areas covered are (a) practical, (b) family, (c) emotional, (d) social, (e) physical, and (f) information. While most of the topics identified are those identified within the NCCN (2011) Screening Tool that the measure was adapted from, there are some age-specific items that have been included based on feedback from the Australian AYA clinicians and AYA patients.

The results of the needs assessment can be divided up into three levels of clinical management. These are (a) high risk needs that require immediate intervention, (b) high risk histories that require close monitoring and priority Care Plan appointments, and (c) normal responses that require standard patient management.

Recommendation.

DT Score of 5 or more + High Risk Needs = Immediate Intervention

DT Score of less than 5 + High Risk Needs = Priority Care Planning

Practical concerns – Housing. Transport. Finances

Unlike adult patients, for a young person without parental support, these practical issues may be close to impossible to address during a time of turmoil without the support of the AYA clinician to facilitate workable outcomes. A young person must have a safe and secure home to live in, a safe mode of transport to get to and from treatment, and the financial capacity to pay for it. Referral to appropriate personnel (for example, Social Work or CNC) as directed by the policies and procedures of the treating organisation should occur in a timely manner.

Education

Young people in their final years of secondary school should receive information and support immediately to assist them to manage their education while undergoing treatment.

Family concerns – Care of Children. Violence

There may be a number of family related concerns highlighted by the young person. Not all will require immediate intervention. Those that do require immediate follow-up include concerns relating to the care of children and family violence. However, as the AYA-POST does not identify these directly, the clinician must explore a high needs score on the Family Concerns section to determine the root cause of the worry. While a referral to Social Work is generally recommended for the management of Family Concerns, organisational procedures should be followed where violence is identified to ensure that local jurisdictional statutory requirements are addressed.

Emotional concerns – Excessive sadness. Despair. Hopelessness. Loss of meaning or purpose.

These factors could indicate that the young person may be a risk to themselves and a prioritised referral to an appropriate psycho-oncology service (social work, psychology, psychiatry) is recommended. School refusal, increased use of drugs and/or alcohol, and risk-taking behaviours may be secondary

indications of emotional concerns. These issues should also be considered when interpreting the level of concern and the most appropriate referral pathway.

Physical concerns – Pain.

Pain must be addressed as a priority as “distress cannot be controlled if pain is not controlled” (NCCN, 2011). If pain is indicated on the needs assessment, referral to an appropriate member of the treating team should occur in a timely manner. Consultation should be sought with the young person’s primary oncologist and, where additional pain complexities are identified, consultation may be required from specialist pain and palliative care services. Additional physical concerns requiring timely follow up include tingling in hands or feet, nausea or vomiting, high temperature or fever. In these instances, institutional policies should be followed to ensure the safety of the patient.

Information concerns – Problems understanding information.

If the young person does not understand (a) the information being provided, (b) the seriousness of the health concerns discussed, (c) the dates for treatments, or (d) health indicators that represent a high risk, they are at risk to themselves. These information concerns should be addressed by the AYA worker at the time of the AYA-POST administration by direct action or referral to appropriate personnel. Lack of information or a sense that one does not feel listened to or involved in decision making can be possible pre-cursors to adherence problems in the future and should be tackled early. Written information concerning rights to privacy, confidentiality and decision making (including assent) should be provided as a matter of course and questions regarding these topics should be encouraged and regularly sought.

Recommendation.

DT score of 5 or more + High Risk Histories = Immediate Intervention

DT score of less than 5 + High Risk Histories = Priority Care Planning

Examples of High Risk Histories

History of psychiatric disorder or depression, alcohol and/or substance abuse, cognitive impairment, severe comorbid illnesses, social isolation, cumulative stressors and communication barriers.

Management

These issues represent past events and may not be identified within the AYA-POST. Standard patient management during initial clinical consultations should identify whether many of the indicators of high risk histories are present. It is incumbent on all members of the treating team to pass such

information on and to act on such knowledge in a pre-emptive manner to limit the potential for adverse clinical outcomes. Ideally this should be achieved through information sharing platforms, such as clinical documentation and multidisciplinary team meetings, and may involve direct consultation with those services involved with past episodes. If a patient has a high risk history the Care Plan appointment should be made a priority and a parallel referral for a full psychological assessment should be considered. Although these factors do not require immediate intervention if high distress is not identified on the distress thermometer, patients with these factors should be closely monitored throughout their treatment so as to identify any changes in coping during the early stages or to alert those already providing support and involved with the young person. A failure to flag for high distress in these scenarios should not preclude intervention based on good clinical judgment.

Recommendation.

DT score of less than 5 + Normal Response = Standard Patient Management

Examples of Normal Distress Response

Symptoms associated with a normal distress response include fears, worry, and uncertainty about the future; concerns about the illness and treatment effects and side effects; sadness about loss of good health; anger and the feeling that life is out of control; poor sleep, poor appetite, and poor concentration; and preoccupation with thoughts of illness and death. Other psychosocial concerns, such as worries about peer relationships, concerns about the coping of family members, or reservations about how to continue with education or employment are all considered to be part of the normal psychosocial response to cancer diagnosis and treatment.

Management

The clinical management of mild distress involves (a) the provision of information to normalise the common distress symptoms, (b) the provision of information regarding the psychosocial management of distress symptoms (c) the provision of information detailing available support options (as per information provision section below), and (d) the routine support and management of the treating team that includes creating an environment within the treating relationship that enables the patient to express their fears and concerns openly and honestly with their treating team.

Information Provision (Step Three)

The topics identified in the ‘tick box’ section in the top right hand corner of the AYA-POST are

those considered to be essential information that should be passed on to all patients whenever the AYA-POST is completed. Providing the visual 'tick box' section serves a dual purpose; (a) it provides a 'double check' for the clinician to ensure they have covered important areas and (b) it provides a prompt for the young person to ask questions about the topics identified.

At some point during the administration of the AYA-POST the patient should receive information on all of the tick box points. Information topics that may require immediate follow up due to time implications include (a) clinical trials, and (b) fertility preservation. If the patient indicates that they require additional information or referral in these areas, the response should be swift. Information relating to the remaining topics can be further discussed during the Care Plan appointment.

While limited resources for AYA patients were available in the past, the National Youth Cancer Service is currently developing a comprehensive range of common fact sheets covering a range of topics.

Recommendation

- **Suggested Web Sites**

The AYA demographic is extremely computer literate. It should be assumed that young people will search for further information on the internet. It is important to support young people in this endeavour by providing them with websites that are safe, authoritative and age appropriate. This does not preclude the use of resources that are from less recognised sources, merely that they should preferably be vetted by clinical staff before being used.

- **Clinical Trials**

All AYA patients should be considered for entry to any clinical research trial for which they are eligible. If an appropriate clinical trial is not available, or the young person chooses not to participate, treatment should be based on agreed treatment protocols.

- **Psychosocial Support Options**

A list of support options, including those (a) within the treating institution, (b) within the community, and (c) online, along with (d) those that are age-specific, and (e) those that are disease specific, should be provided to every young person at the time of diagnosis and again at subsequent screens. While not all young people will be looking for additional support during the early stages of their diagnosis when they may be experiencing 'information overload', it is important that they have access to such

information throughout their patient journey. They will then have the information required to access support when needed and/or if their situation changes.

- **Entertainment**

Information detailing availability of entertainment equipment and recreational activities should be provided to (a) assist young people to feel 'normal', (b) limit the rigid structure of the hospital setting, and (c) promote social interactions. This may include information regarding AYA relevant music, electronic games, magazines, computers with internet access, and books provided by a library service or volunteer program. Other recreational activities that are run by the hospital that are age based or AYA relevant should also be detailed. Details of where young people can access drinks and snacks should be included along with options for take-away meals.

- **Home Comforts**

To encourage a treating environment that promotes a sense of familiarity and safety, information should be provided prior to the first treatment suggesting ideas of 'home comforts' that the patient can bring with them. Ideas include pillows, doonas, photographs, games, computers, portable tablets, and music players.

- **Alcohol and Drug Use**

Alcohol is regularly the centrepiece of socialisation for the AYA age group. Australian statistics indicate that 21% of 16–17 year olds, 45% of 18–19 year olds and 62% of the older AYA age group consume alcohol on a weekly basis (AIHW, 2005). Information should include (a) safety information about drug and/or alcohol use during treatment, (b) health recommendations concerning use of drugs and/or alcohol during treatment, and (c) details of where to go for further information and support if required.

- **Fertility Preservation**

Any risks to future fertility should be discussed with the patient prior to commencing treatment in a proactive manner. Information should be provided in a clear and direct manner. Referrals to fertility preservation services should be made promptly whenever required. Verbal discussions should be accompanied by age appropriate resources.

- **Communication Tools**

It is important to provide young patients with tips for communicating with hospital professionals to assist them to build their confidence and get their message across within a potentially intimidating environment. The information provided should

also encourage the young person to participate in their own care by (a) writing things down (for example: “I have some questions that I have written down. Could we please go through each one?”), (b) asking clinicians to slow down if they are not understanding information or if the appointment is moving too quickly (for example: “I am feeling a little rushed. Could we please slow things down a little bit?”), (c) highlighting unfamiliar words or terms and seeking clarification (for example: “I am sorry. I did not understand what you just said. Could you please explain it to me in a different way?”), (d) asking questions, and (e) summarising each appointment at the end to facilitate understanding (for example: “I have been taking notes during this appointment. Could I read them back to you to make sure that I have it right?”)

- **Sexual Health**

The topic of sexual health and sexuality can be neglected during the standard management of AYA patients. Raising the issue of sexual health during the early stages of a patient’s journey provides the young person with permission to discuss any concerns and serves to normalise these issues as part of standard patient management.

- **Education Support**

Education is consistently rated as a high concern for newly diagnosed AYA patients. The provision of information regarding education options serves to arm the young person with the knowledge they require to manage their concerns.

Discussing education during the early stages of diagnosis and treatment highlights to the patient that continuing education throughout treatment is possible and it enables the institutions involved to plan for any special requirements to support the young person during this time (ie special consideration applications).

- **Role of Key Worker**

The role of the key clinician is to provide a face for the treating team and a contact person for the patient journey. Key workers typically (a) provide practical and emotional support to the young person and their family, (b) develop the patient Care Plan, (c) schedule and administer regular psychosocial screening, (d) liaise with relevant community agencies, (e) liaise with educational institutions, and (f) support the young person as they move along the patient pathway. While most commonly a nurse or social worker, the person designated to perform this task may change over time with changing circumstances.

Care Plan Appointment (Step Four)

An appointment for the development of the Care Plan based on the results of the AYA-POST should be made immediately following the completion of the screen. The recommended timeframe between screening and Care Plan development is within two weeks. The timing of the appointment would depend on the results of the screen. For those patients who (a) have identified high levels of distress, (b) display significant risk factors, or (c) have identified concerns on the needs assessment that require immediate intervention, a Care Plan appointment should be made as soon as possible.

If there are issues that require immediate intervention – examples include referral for pain management, the provision of further information regarding fertility preservation, management of emergency housing issues, or the lodging of special consideration requests for students undergoing final exams– normal hospital protocols should be followed prior to the Care Plan appointment. While it is up to each AYA team to manage their own appointments, it is recommended that time be allocated each week to ‘emergency’ or ‘at risk’ Care Plan appointments to minimize the wait for young people most in need.

Signatures (Step Five)

The final section of the AYA-POST is the signature section at the bottom of the page. This is included to promote the ‘teamwork’ approach to patient management. The dual signatures represent the shared understanding between the patient and the clinician that the next steps have been discussed and agreed upon. By including the dual signatures, the patient identifies that they (a) have completed the measure, (b) understand the process and (c) have been informed of the next steps, while the clinician acknowledges their role in the management of the patient and the requirement to schedule an appointment to develop the Care Plan. It is incumbent on the clinician to ensure that all of this is understood by the patient and that any information is repeated and/or clarified until both parties understand the issues and the next steps. This is an important part of the process as it immediately sets out for the patient the role that they have to play in their own health management and the responsibility they have in ensuring that those working with them during their treatment are armed with all the information they require to do their job.

Care Plan

The goal of the Care Plan is to provide a means for clinicians to collate relevant information from the AYA-POST and develop a strategy to manage issues raised. The Care Plan (a) is related to the AYA-POST, (b) is quick and easy to complete, (c) is AYA specific, (d) can be used as a communication tool between professionals, (e) can be updated when necessary, (f) is completed in partnership with the patient, (g) provides details for self-management by the patient where appropriate, and (h) incorporates a 'flag' system for highlighting areas of major concern.

Administration Guidelines and Clinical Recommendations

The Care Plan requires a quiet setting and approximately 45 to 60 minutes to complete. Depending on time available and patient need, the clinician can complete the Care Plan by (a) using a simple coding system, or (b) documenting full details in the space provided. The issues identified by the patient in the AYA-POST are addressed within the Care Plan based on a priority system determined by a patient rating of urgency. Importantly, details of any referrals made must be included on the Care Plan. This ensures that the young person is fully aware of names and contact details for any follow-up and can manage their own care if desired. However, this 'self-management' approach should be an option for the patient to choose and not an assumed part of AYA psychosocial care.

Rate Items (Step One)

Items that have been identified by the patient on the AYA-POST as contributing to current distress levels should be highlighted on the Issue List. This can occur by crossing out any issues not identified. The remaining items become the working list for the development of the Care Plan. In discussion with the clinician, the patient then rates each item on the list using the rating system; L = low concern, M = medium concern, H = high concern, UR = urgent response required. This rating system will assist in the prioritisation of issues.

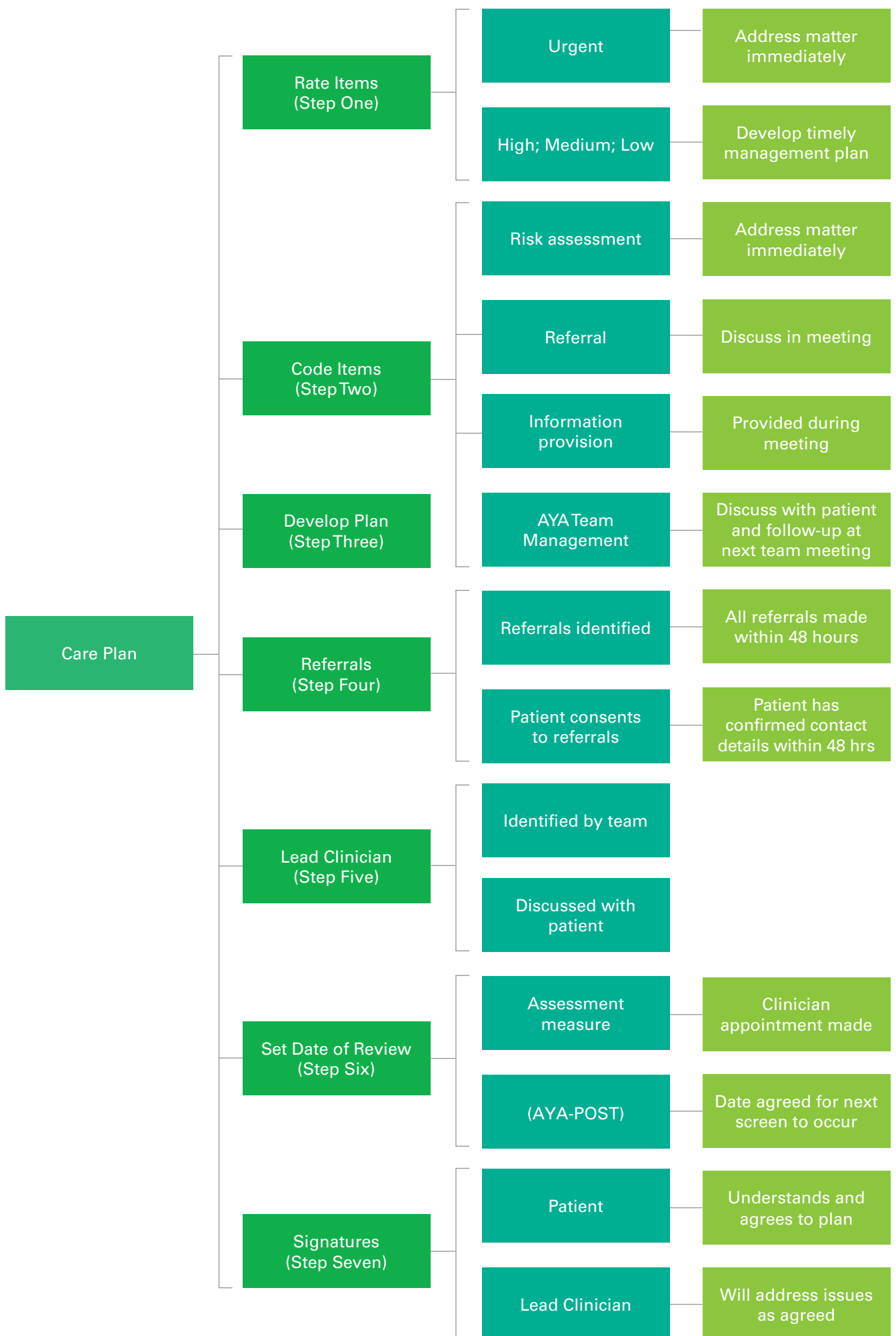
Recommendation

This is a subjective patient rating that should correspond to the urgency with which the patient feels assistance is required. While all areas of need identified on the AYA-POST will be discussed over time, this process assists the patient to understand that issues will be dealt with on a priority basis. The rating system assists the clinician to identify which issues are most pressing for the patient as these may not always correspond to the assumptions of the clinician.

An example of how the patient may wish to consider their ratings;

- **Low concern** indicates that it is something the patient has thought about, but it is not hindering their daily activities. Nor will it influence their capacity to attend clinical appointments or cope with treatment side effects.
- **Medium concern** indicates that the issue has had some influence upon the daily activities of the patient, and while they currently feel like they are managing, further assistance would be helpful. Furthermore, if not attended to, there is the possibility that the issue could become more problematic in the future and negatively impact upon coping.
- **High concern** indicates that the issue is impacting upon the daily activities of the patient. The issue needs to be addressed as a priority in order for the patient to continue to cope with treatment.
- **Urgent response required** indicates that the patient does not feel that they can continue to cope with the status quo. The issue needs to be addressed immediately.

Figure 4. Care Plan Flow Chart



Code Items (Step Two)

Once rated, the clinician then discusses with the patient the next steps in addressing the issues identified. A coding system is once again employed in order to simplify the process and enhance patient understanding. The coding system covers all of the basic clinical responses to indicators of need; A = assessment, R = referral, I = information provision, RA = risk assessment, ATM = AYA team management.

Recommendation

The responses identified by the clinician, and the reasons behind each response, should be discussed and explained to the patient during this process.

- **Assessment** indicates that further patient information is required to provide the best possible assistance in relation to this issue. The completion of the AYA Psychosocial Assessment Measure would provide a greater understanding of the young person, the influences in their life, the risk and protective factors, and goals for the future. Thus enabling the clinical team to work more effectively to support them throughout their treatment.
- **Referral** indicates that there is an individual (for example, social worker), team (for example, palliative care team) or group (for example, Canteen) that would be best placed to manage the issue identified.
- **Information provision** indicates that the issue identified is due to the absence of sufficient information. It is anticipated that by providing age-appropriate and detailed information about the topic identified, the needs of the patient will be addressed. It is the responsibility of the clinician to follow up at subsequent meetings to ensure that the issue has been addressed. It should also be explained to the patient that, if they have further questions or concerns once the information has been provided, they must contact their Lead

Clinician or other member of the treating team to discuss further. Issues that may be addressed through the provision of information include those identified within the tick box section of the AYA-POST (for example, Support Options, Communication Tools, Websites), further information about the treatment and/ or disease, or information about transport options and parking costs.

- **Risk assessment** is associated with immediate concerns about the well-being of the patient. The clinician must address any immediate risks of self-harm or suicide and respond immediately. If there are any concerns, an immediate mental health consultation should be sought. Clinicians are encouraged to follow institutional policies and procedures when responding to high risk situations.
- **AYA team management** indicates that the issue identified is one that commonly affects AYA patients and is routinely addressed as part of the standard patient management within the treating institution. The issue identified does not require any referral, information, or psychosocial assessment for best-practice care; it will be addressed as standard practice. Examples may include facilitating the relationship between the patient and their school to assist with ongoing education, discussing ideas to limit the number of important events the patient misses out on, or discussing ways to help manage the stress and distress of other family members.

Develop Plan (Step Three)

If time allows, the clinician should then discuss and write down the steps involved in each of the response codes listed in Step Two. For example, the particulars of what "A for Assessment" means should be fully detailed. This enhances the patient's capacity to be involved in their own care and ask questions where appropriate.

Referral Details (Step Four)

The names and contact details of all referrals should be listed under the Contact Person section. Once identified here, the clinician is required to make the referral within the next 48 hours and report back to the patient within this time with any additional information.

Recommendation

- There should be access to specialist psychological support if required. Treatment centres without ready access to such services are encouraged to develop a referral directory of appropriately trained mental health professionals in the community for referral.
- All relevant details for clinical referrals, both internal and external, should be kept within easy access so that they can be provided to the patient during the Care Planning session.
- Information regarding community support should also be accessible and provided as appropriate.

Lead Clinician (Step Five)

The Care Plan incorporates a space to record the details of the Lead Clinician identified to manage the patient's care. This serves a number of purposes; firstly, it provides the details of the clinician that the patient can contact to address any concerns or answer any questions. Secondly, it provides details of a contact person to other individuals involved in the patient's care that may receive copies of the Care Plan (for example; ward staff, GP's, shared care clinicians, palliative care clinicians). Finally, it promotes the discussion of patient management and the appointing of key workers among the treating team.

Recommendation

- Ideally, the Lead Clinician will be conducting the Care Planning Session. If this is not the case, it is recommended that the treating team discuss who will be the Lead Clinician for the patient prior to the Care Planning appointment. This ensures the patient can be informed of the name and contact details of the relevant person during the Care Planning meeting.

Date for Review (Step Six)

The first review is to be set approximately six to eight weeks following the development of the Care Plan. This review should coincide with eight to ten weeks post-diagnosis. Depending on (a) the resources available and (b) the needs of the young person, the review will either consist of the administration of a second AYA-POST or the completion of the full Psychosocial Assessment Measure.

Reviews should then occur at approximately six months post-diagnosis and at significant points throughout the patient journey. It is the responsibility of both the patient and the Lead Clinician to anticipate and identify when these significant time points occur.

Recommendation

- A date for review should be discussed prior to the completion of the Care Planning appointment. This is to promote adherence to the care pathway and provide a sense of consistency for the patient.
- While it should be made clear to the patient that the time and date of the forthcoming Screen can be revised if required, the benefits of a confirmed follow-up appointment (ie. that their psychosocial health is a priority and further support is never far away) should not be underestimated.
- It should also be made clear to the patient that if any issues or needs arise prior to the scheduled appointment they are to contact the Lead Clinician for assistance.

Signatures (Step Seven)

There is a signature section at the bottom of the Care Plan that requires both the Lead Clinician and the patient to complete to highlight their understanding of the outcomes of the Care Plan and the next steps identified.

Psychosocial Assessment Measure

While many of the topics in the Assessment Measure are similar to those identified in the AYA-POST, the information obtained is significantly more detailed and provides a greater opportunity to prompt the young person for further detail or allow them to elaborate on the areas they feel to be of greatest priority. By understanding the goals, resources, past experiences, current relationships, and future expectations of the patient, treating teams are better able to recognise what interests and motivates them. This can then assist with adherence (“adherence hooks”) and can support the young person to maintain interests and goals outside of their diagnosis and treatment. Knowing the young person well can assist staff to anticipate future problems and avoid potential crises. The information gathered using the Assessment Measure forms the foundation for the development of a Working Care Plan – which represents a more detailed Care Plan that highlights key risk and protective factors, adherence hooks, and survivorship plans.

The readily available HEADSS assessment (Goldenring & Cohen, 1988) is the foremost psychosocial assessment measure used in adolescent health and medicine. It is well known and well respected. The AYA oncology psychosocial assessment measure uses the HEADSS as its foundation with revisions to (a) improve relevance for the AYA cancer population, (b) address suitability for the older AYA age group, (c) incorporate the notion of “normalizing” the cancer experience, and (d) identifying considerations for healthy survivorship. The Assessment Measure presented herein is an extension of a similar measure developed in 2006 by ONTrac@ Peter Mac, the Victorian Youth Cancer Service. Additional prompts for information gathering and the addition of a ‘Clinical Response’ section have been incorporated in this latest version. Once again, the clinical recommendations provided below are to be used as a guide only. They are not a substitute for clinical experience or expertise.

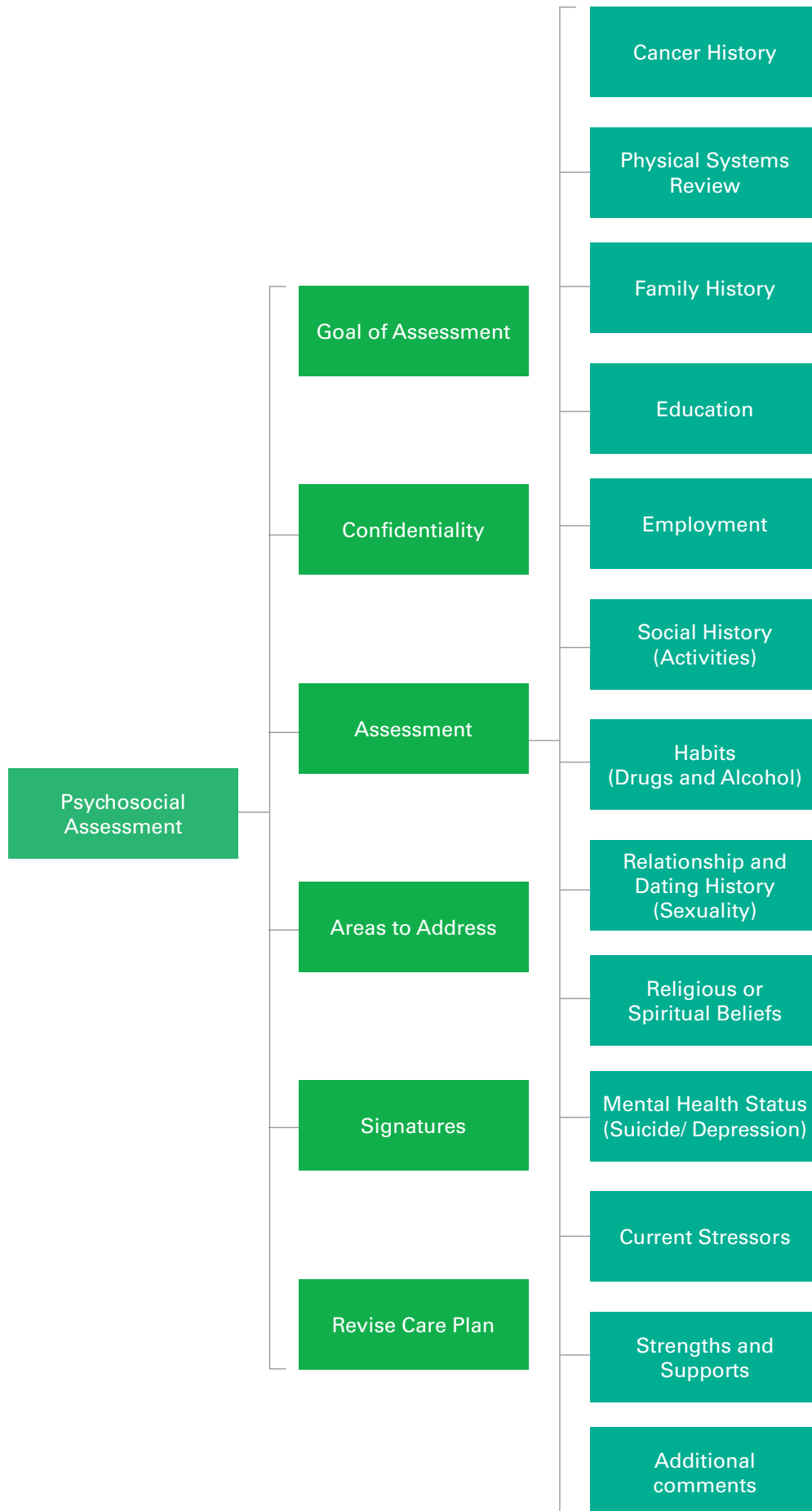
Administration Guidelines and Clinical Recommendations

A complete administration of the measure requires a significant period of time. While a simple, less detailed assessment may be able to be completed in a single one hour appointment, a more detailed assessment will require more time (between 90 minutes and two hours with some variability). However, there is flexibility in regards to the administration of the measure as it can be conducted (a) in a single session, or (b) over a number of separate appointments. It should be remembered that, while the administration of the assessment is an opportunity to garner valuable information from the patient, it is also a valuable opportunity to continue to build rapport and trust.

The assessment should be conducted in a quiet

and private setting. Information should be gathered in a calm and deliberate manner without time pressures. Young people need to be made to feel that their experiences and any aspects of their life that they wish to share with the clinician will be listened to and valued. How this is managed within the different clinical settings is best decided by the individual AYA teams. The only stipulation is that, resources permitting, every young person should have the opportunity to complete a full assessment. This will enable the treating team to be best able to manage their care in a preventative capacity and support healthy survivorship. In settings where resources are limited, those patients recognised to be at risk of a negative psychosocial outcome based on the AYA-POST findings should receive a full assessment to ensure that the Care Plans developed are fully informed with risk factors identified.

Figure 5. Flow Chart of Psychosocial Assessment Measure



Goal of Assessment

Many young people may not have had contact with health services or a mental health professional prior to their diagnosis. They may find the experience anxiety provoking and intimidating. It is important that the young person is assured that the process is preventative. It should be explicitly stated that the motivation for the assessment is recognising the inherent stress associated with a diagnosis during the AYA years. It is not an indication that the team feels the young person is not coping. It is important that the role of the assessment in treatment planning is explained. This includes highlighting its role in supporting the young person in other areas of their life, throughout treatment and into survivorship.

Confidentiality

Confidentiality is a key aspect of working with young people. Young people may feel reluctant to disclose personal and sensitive information prior to understanding the confidentiality arrangements of the assessment. Before conducting the assessment, the clinician must inform the patient what information will remain confidential (for example, the difficulties in their relationships with parents or partner), what information must be disclosed or acted upon (for example, if the young person is in danger, if they are a danger to themselves, if they are a danger to others) and what is open to a negotiated arrangement (for example, those issues that may impact upon the team's ability to provide the best care possible). Any institutional requirements for documenting assessments and patient appointments must also be discussed.

Detailed History of Cancer Experience

Providing the young person with the opportunity to tell their 'story' from start to finish can be a cathartic process. It is also a gentle way to promote discussion and to build trust as most young people are very comfortable talking about their medical history. Furthermore, hearing the patient story from the perspective of the young person has the added benefit of highlighting to the clinician the issues that are most important to the patient.

Suggested Prompts: I am really interested to learn more about what your life has been like over the past few weeks – Are you able to tell me 'your story' from the time you first realised something was not quite right to how you ended up here talking to me?

Recommendation

- Take time to listen to everything the young person has to say. Give them time to tell their story.
- Focus on building rapport and trust. Do not rush the process.
- Take note of any issues that create a strong emotional response in the young person. What issues are most pertinent to their story? Was it that professionals or other people did not believe that they were feeling unwell which led to a delay in diagnosis? Was it that the timing of the diagnosis meant that they could no longer go on the Student Exchange they had planned? Was it that the new relationship they had begun had not survived the diagnosis and early treatment period? Each of these issues will impact upon their emotional coping during their treatment and may not have been recognised as important by those around them in the context of "just getting better".
- Acknowledging their distress when talking about these issues is the first step to helping them move forward.

Physical Systems Review

A cancer diagnosis is a stressful experience and some young people may experience physical symptoms associated with this stress. It is important to conduct a brief screening for symptoms of anxiety, depression or other mental health issues that may require referral.

Suggested Prompts: Over the past month, or since your diagnosis, how has your sleeping been? Any trouble getting to sleep or waking up in the early morning? How have your energy levels been? Have you noticed any change in your appetite? Changes in your weight? Do you ever notice that you are short of breath or that you have trouble catching your breath? Do you ever experience a racing heart? Have you have any more headaches than usual?

Recommendation

- A referral to a mental health professional as per institutional protocol is recommended if any sudden or significant changes in the areas of sleep, appetite, energy, weight, or heart rate that do not appear to be directly related to the physical and/or medical implications of the cancer treatment are reported.
- Any noticeable changes in affect or appearance since previous meetings should also be noted.

Family History (Home)

Working with AYA cancer patients requires a thorough understanding of their family environment. Most young people will either be living at home, be forced to return home, or be relying heavily on the support of their family throughout their illness. The successful management of the AYA patient cannot occur without understanding the impact of the family and the additional stressors inherent within the family environment of the patient.

Suggested Prompts: Who lives at home with you? Where do you live? How long have you lived there? How many siblings do you have? Are they healthy? Are there any new people living in your home? Are your parents healthy? (physically & emotionally) What do they do for a living? What are the rules like in your home? Who makes the rules? What happens if the rules are broken? Is there any violence occurring in your house? Do you get along with your parents? What kind of expectations do your parents have about you? How do you get along with your siblings? Who in your family are you able to talk with about things? Can you share with them your thoughts about your cancer experience? What kinds of things create arguments in your house? Have there been any significant experiences in your family that has shaped it to be what it is today? (i.e. deaths, divorce, accidents, illnesses...) Is there anything you would change about your family?

Recommendation

- Understanding who makes up their family, what their family relationships are like, who is available to support the patient, and what family stressors are present will enable the clinician to best develop a plan to support the young person throughout their experience.
- Help the patient highlight who the best family members are for providing support when needed and assist them to identify which family relationships may drain them of their strength during this time.
- It is important to look for both resilience and risk issues within the family.
- If the patient identifies stress associated with the family management of the illness, support and information should also be provided to relevant family members.

Education

All young people of school age have the right to continued education despite their medical situation and the treating team has a responsibility to facilitate this. If the needs of the patient and the needs of the school can be supported, the likelihood of re-integration problems following treatment completion can be minimised. Further, if well supported and coordinated, a patient can continue on with some schooling throughout their treatment period. This can be a great relief and motivator for the AYA patient and can be used as an 'adherence hook' when needed.

Older AYA patients who are attending University studies or TAFE courses should also be supported in their education decisions. This may be (a) continuing with a full course load, (b) continuing with a reduced course load, or (c) deferral of studies. In order to achieve this, a thorough understanding of the educational needs of the patient is required.

Suggested Prompts: What school/university/TAFE do/did you go to? What do/did you like best and least about school/studies? What were your most recent grades? Have these changed recently? Have you ever failed, repeated, or skipped school years? How much school/study have you missed over the past 3 months? How do or did you get along with your teachers/lecturers/tutors? Many young people experience bullying at school, have you ever had to put up with this? How has your school/university/TAFE responded to the news of your diagnosis? What could your school/university/TAFE do to help you during this experience?

Recommendation

- Facilitate an agreement between the patient, treating team, and school/university/TAFE that can address some of the difficulties that the young person may face in managing their education during treatment.
- Ensure that the patient has a private space to study when needed.
- Liaise with the school/university/TAFE in relation to special consideration needs.
- Assist the school/university/TAFE to manage the responses of the other students.
- Support the continued connection of the patient to the school/university/TAFE with extra-curricular activities where possible.
- Consider the long term complications related to the cancer therapy and the young persons continued engagement in education after therapy is completed.

Employment

By virtue of their age, AYA patients will be new to the workforce and many will be employed in casual or part-time positions. They may have limited sick or annual leave and may not have had the opportunity to build the “goodwill” of employers the way older patients may have. Employment, including rights at work, leave entitlements and access to Centrelink support, are all areas that need to be canvassed.

Suggested Prompts: Are you currently employed? Have you recently been employed? What do/did you do? How many hours do/did you work a week? What kind of jobs have you done previously? What kind of work do you hope to do in the future? How has your workplace responded to your diagnosis?

Recommendation

- If indicated, obtain patient consent to provide support letters.
- Support the young person to access information regarding Centrelink entitlements.
- Support the young person as they navigate the Centrelink system to obtain entitlements.
- Explore opportunities for access to early superannuation.
- Where possible, liaise with employers in relation to implementing flexible working conditions for the patient in order to remain employed.
- Refer to employment support agencies to access individualised assistance for the young person re-entering employment post treatment.
- A referral to a social worker to manage these issues should be considered.

Social History (Activities)

Peer relationships are central to the world of the developing young person. The treating team has an obligation to assist the AYA patient to manage these relationships. This includes facilitating ongoing relationships with friends and enabling the young person to attend important ‘rites of passage’ events throughout their treatment period. It is important that the young person has the opportunity to continue to live as normal a life as possible so as to enhance peer support, facilitate treatment adherence, improve coping and improve survivorship.

Suggested Prompts: What do you do for fun? How do you spend your spare time? What things do you do with your friends? Do you have a large group of friends? One best friend? A few very close friends? Are your friends of the same sex or a mixed crowd? Do you spend time with your family? What does your family do together? Do you do any regular sports? Are

you a member of any groups or clubs? What kind of TV do you watch? What are your favourite shows? How much TV do you watch? Do you read for fun? What kind of things do you enjoy reading? Do you use the internet socially? What is your favourite site?

Recommendation

- Provide the young person with information to assist them in managing and maintaining their peer relationships. This may include information on how to talk to friends about their cancer diagnosis and treatment, and tips on maintaining friendships during treatment.
- Encouraging peer interactions when the AYA is an in-patient. For example, encourage ‘pizza nights’ with friends, make sure the ward is a welcoming place to visit, provide a private place for young people to get together, and offer some education to friends to alleviate their concerns.
- Facilitate the patient’s attendance at ‘rite of passage’ events such as 18th or 21st birthday parties, school or university graduations, school recitals, sporting grand-finals, and the like.
- Encourage treating teams to be aware of important social events in the life of the young person and promote flexibility where possible around treatment dates, consultation times, and procedures.

Habits (Drugs and Alcohol)

Alcohol is regularly the centrepiece of socialisation for the AYA age group. Australian statistics indicate that 21% of 16–17 year olds, 45% of 18–19 year olds and 62% of the older AYA age group consume alcohol on a weekly basis (AIHW, 2005). There are two main issues that need to be addressed with AYA patients. These are; (a) patient safety – which involves addressing any complications or dangers that may arise from using alcohol and/or drugs during treatment, and (b) educating the young person to make the best decisions for them regarding the use of drugs and alcohol during their treatment period. Young people may be particularly reluctant to disclose issues concerning drug and/or alcohol consumption if confidentiality is not assured. This is crucial to the management of this topic.

Suggested Prompts: Many young people experiment with drugs, alcohol, or cigarettes. Have you or your friends ever tried them? What have you tried? How much and how often? What effects did they have on you? Have you done anything that you now regret? Do any of your family members drink alcohol, smoke or use other drugs? If so, how do you feel about this – is it a problem for you? Have you or your friends ever tried any other drugs? Specifically what?

Have you ever used a needle? Do you regularly use other drugs? How much and how often? How do you pay for your cigarettes, alcohol or drugs? Have you ever been in a car accident or in trouble with the police? Were any of these related to drinking or drugs?

Recommendation

- Issues requiring particular consideration in a medical capacity include management of drug dependency, exposure to blood-borne illnesses, significant interaction with co-morbidities and interactions with medically prescribed drugs. Appropriate referrals or education should be undertaken if these issues are of concern.
- All other patients require clear, confidential, and non-judgmental information about the risks associated with using drugs and/or alcohol.
- If their behaviours do not present an immediate risk to themselves or their treatment, what they then choose to do with the information provided to them is a personal choice.

Relationship and Dating History (Sexuality)

While this may be a topic the patient is reluctant to initiate, almost all will appreciate an open and frank discussion about how their treatment will and will not affect their sexuality and their sexual behaviours. Furthermore, due to the potential isolation from peers and normal sources of information and discussion, general sexual health questions may also require exploration. Consideration should be given to the needs of young people in both heterosexual and homosexual relationships.

Suggested Prompts: Are you involved in a relationship? Have you been involved in a relationship? How was the experience for you? How do you see yourself in terms of sexual preference (i.e. gay, straight, bisexual)? Have you had sex? Was it a good experience? Are you comfortable with sexual activity? Do you use contraception? Have you ever had an experience in the past where someone did something to you that you did not feel comfortable with or that made you feel disrespected? If someone abused you, who would you talk to about this? How do you think you would react? Has your oncologist, or other health professional, discussed with you about having sex while on treatment?

Recommendation

Depending on the issues identified, the clinical response may include

- the provision of basic sex education.
- facilitating referrals to sexual health clinics.

- advocating on behalf of the patient with the treating team.
- gathering specific sexual health questions from relevant professionals.
- providing relationship support to partners.
- providing sexual health information to partners.

Religious or Spiritual Beliefs

The adolescent and young adult life stage is a time of existential/spiritual growth. A cancer diagnosis can further trigger existential questioning that can be very important to how the young person makes sense of, and copes with, their cancer journey.

Suggested Prompts: Has your cancer led you to search for meaning in life or meaning in this experience? Have you done any other spiritual exploring? Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stressful experiences? What importance does faith or belief have in your life? Are you part of a spiritual or religious community? How has your diagnosis impacted upon your spiritual beliefs?

Recommendation

- All those working with young patients must be mindful of these existential needs.
- All young people should have the opportunity to explore these issues in a trusting relationship.
- While spiritual support may not always require specific pastoral care services, referral to such services should be considered if indicated.

Mental Health Status (Suicide/Depression)

Many of the issues that identify a young person's mental health status or risk for pathological functioning will already have been addressed throughout the assessment. These include family problems, changes in school performance, changes in friendships, sexual acting out, drug and/or alcohol abuse. However, direct questions to be addressed at this stage include a history of mental health problems or suicide in family members or close friends. If the assessment indicates that depression is likely it is important to ask directly and clearly about self-harm.

Suggested Prompts: How do you feel in yourself at the moment on a scale of 1 to 10 (with 1 being terrible and 10 being fantastic)? Do you ever have really good/bad times? Do you ever have worries that keep you awake? What sort of things do you do if you are feeling sad, angry, or hurt? Is there anyone you can talk to about these things? Do you feel this way often? Some people who feel really down often feel like hurting themselves or killing themselves, have

you ever felt this way? Have you ever tried to hurt yourself? What prevented you from doing so? Do you feel the same way now? Do you ever feel that life is just not worth it? Have you ever thought of just ending your pain once and for all? How strong are these feelings at the moment? Do you have a plan? What is your plan?

Recommendation

- Young patients may display their distress in ways that are different to adults – it is important to be vigilant to age-appropriate expressions of distress and the concerns of significant others that the behaviours of the young person are ‘out of character’.
- Be vigilant to comments about feeling “bored” as this can be an indicator of depression in this age group.
- Feelings of hopelessness, changes in eating patterns, sleep disturbance, and diminished affect should be noted.
- If the young person has a history of previous mental health issues, determine what interventions they had in the past, what worked for them and what did not work.
- Determine if the mental health issue identified requires referral.
- Determine the timeliness of the referral required (for example, is the patient currently at risk? Should they be allowed to go home? Should family members be notified of your concerns? Should they wait for a risk assessment by a mental health professional?).
- A referral directory of appropriate community and private mental health professionals should be developed and utilised if access to internal psycho-oncologists is not possible or appropriate.
- Clinicians are encouraged to follow institutional policies and procedures when responding to high risk situations.

Current Stressors

With everything that is going on in the life of the young person, they may feel pressure from other areas of their life that are not related to their cancer experience. It is important to know all aspects of the pressure and stress going on in their life in order to provide a wholistic plan of support during their experience.

Suggested Prompts: With everything that is going on in your life at the moment, what is creating the greatest stress for you? What about your cancer experience is the most worrying? What is it outside of your cancer experience that is creating the greatest stress?

Recommendation

- Identify areas creating undue additional pressure on the young person (for example, difficult peer relationships, concerns about weight loss and/or gain, sibling conflict, upcoming musical recital).
- Provide education regarding the benefits of reducing all stressors during this period.
- Develop management strategy together.
- Discuss who else could help with these stressors.
- Refer for additional support if necessary.

Strengths and Supports

When going through a life threatening experience it is important that the focus of the assessment is not simply on the negative aspects of the patient’s life, but identifies the positive attributes the young person brings to their experience. Asking the AYA patient about their strengths and supports prompts them to identify the traits that will get them through their experience. It also allows the clinician to identify where the young person may need additional support.

Suggested Prompts: What are the things that you have in your life, or within yourself, that are going to help you to get through this experience? What is your usual coping style? (behavioural, affective, cognitive, friends, family, work, school, church, internal coping...)

Recommendation

- Identify areas of strength within the young person and their story (for example, a positive approach to life, close relationship with maternal grandmother, passion for craft activities).
- Provide education regarding how personal strengths can support and sustain them throughout their experience.
- Develop a management plan together that uses these strengths to their greatest advantage.
- Spend time brainstorming ideas about how to get the most out of these positives.

Additional Comments

This section is to add any outstanding issues not previously mentioned. Patients should be encouraged to add any further comments they deem to be relevant – no matter how trivial to the clinician. This is a means to further build a picture of the young person to assist in Care Planning and patient management.

Areas to Address

It is recommended that the assessment is concluded with (a) a brief summary of the assessment outcomes, and (b) a discussion of the areas to address in ongoing psychosocial care of the patient. Feedback from the patient regarding the accuracy of the summary should be sought and any changes or additions should be incorporated. Finally, end the assessment session with a tentative plan for how the young person will be supported over the coming months.

Signatures

The final step is for both clinician and patient to sign the assessment document to indicate that the outcomes are agreed upon and the areas to address have been discussed. The relationship between the patient and the clinician is a collaborative one and both parties have the responsibility to identify (a) if the assessment has not identified the primary concerns or has missed additional issues, and (b) if concerns change over time.

Revise Care Plan

The Care Plan should now be revised to incorporate the outcomes, and further detail, of the Assessment Measure. This may include (a) new referral details, (b) specific management strategies identified from strengths section, (c) additional information regarding drug and/or alcohol use, or (d) suggested ways to support peer interactions on the ward. Any information that can be used to assist other clinicians working with the young person should be incorporated.

Youth Cancer Services

New South Wales and Australian Capital Territory

Sydney Youth Cancer Service

Email: SESLHD-SydneyYCS@health.nsw.gov.au

Mobile: 0400 474 691

Royal Prince Alfred Youth Cancer Service

Email: aya@1h.org.au

Mobile: 0467 730 436

Hunter and Northern NSW Youth Cancer Service

Email: ayaccn@calvarymater.org.au

Phone: 02 4014 4682

Mobile: 0407 398 569

Western Sydney NSW Youth Cancer Service

Email: westernsydneyYCS@health.nsw.gov.au

Phone: 02 9845 2142

Mobile: 0408 732 714

ACT Youth Cancer Support Services

Email: ayancc@act.gov.au

Phone: 02 5124 5788

Mobile: 0478 401 535

Queensland

QLD Youth Cancer Service

Email: QYCS_CHQ@health.qld.gov.au

Phone: 07 3068 5090

Mobile: 0427 828 068

Cancer Care Coordinator: 07 3068 1383

South Australia and Northern Territory

SA/NT Youth Cancer Service

Email: youthcancer@sa.gov.au

Phone: 08 7074 2348

Fax: 08 8429 6101

Victoria and Tasmania

VIC/TAS Youth Cancer Service

Email: ontrac@petermac.org

Phone: 03 8559 6880

Fax: 03 8559 6229

Western Australia

WA Youth Cancer Service

Email: ayaccs@health.wa.gov.au

Phone: 08 6383 3416

Fax: 08 6383 3450

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(Names and titles were correct at the time of the 2011 development of this resource)

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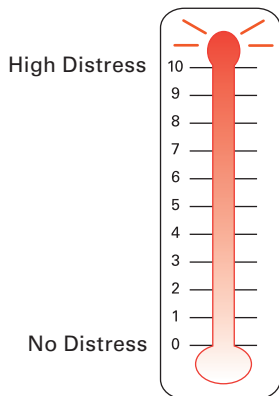
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Appendices

- **Adolescent and Young Adult Psycho-Oncology Screening Tool (AYA-POST)**
- **Adolescent and Young Adult Psycho-Oncology Care Plan**
- **Adolescent and Young Adult Psycho-Oncology Assessment Measure**

1. General Distress

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



Office Use Only:	
Patient Name	
Date of Administration	
Date of Next Administration	

Information Provided:			
Clinical trials		Alcohol and drug use	
Support organisations		Fertility preservation	
Entertainment		Communication tools	
Home comforts		Sexual health	
Recommended websites		Education support	
Lead Clinician			

2. Specific Areas of Need or Concern

In the boxes provided, please indicate which areas have been an issue for you over the past week.

Practical

- Housing or living arrangements
- Education
- Work or career
- Transport or parking
- Bills or finances

Family

- Mum and/or Dad
- Brother(s) and/or sister(s)
- Partner, boyfriend or girlfriend
- Child(ren)
- Other family members

Emotional

- Sadness
- Feeling alone or isolated
- Anxiety or fear
- Guilt
- Boredom
- Anger or frustration
- Extreme moodiness
- Feeling hopeless or helpless
- Feeling confused
- Loss of meaning or purpose
- Loss of faith or spirituality

Social

- Isolated from friends
- Missing important events
- Friends don't understand
- Worry about boy/girlfriend
- Missing doing the "normal stuff" with friends

Physical

- General appearance
- Hair loss
- Breathing difficulty
- Fitness or sporting ability
- Sleeping difficulty
- Constipation or diarrhoea
- Sexual concerns
- Loss of libido (desire for sex)
- Pain when having sex
- Fertility
- Eating or appetite
- Extreme exhaustion or tiredness
- Memory or concentration
- Tingling in hands or feet
- Pain
- Nausea or vomiting

- High temperature or fever
- Use of alcohol and/or drugs
- Other medical worry

Information

- Understanding of information
- Feeling involved in decision making
- Feeling listened to (eg. by doctors, nurses, family)
- Rights to confidentiality
- Rights to privacy

Other areas of concern not listed:

I, _____ understand that the above information will be used by my treating team to develop a care plan for me.

Patient Signature: _____ (Patient's name) Date: _____

Clinician Signature: _____ Date: _____

I am currently participating in a clinical trial or research study. Name of trial(s) or study (if known) _____



Adolescent and Young Adult Psycho-Oncology Care Plan

Office Use Only:	
Patient Name	
Date of Administration	
Date of Initial Care Plan	
Date of Review	

Office Use Only:	
Patient Name	
Distress Thermometer Score	
Details of Lead Clinician	

Rating: L: low concern M: medium concern H: high concern *UR: urgent response
Intervention codes: A: assessment R: referral I: information provision RA: risk assessment ATM: AYA team management

Issue (cross out those not indicated)	Rating	Code	What we are going to do	Contact (name & number)
Practical				
Housing or living arrangements				
Education				
Work or career				
Transport or parking				
Bills or finances				
Family				
Mum and/or Dad				
Brother(s) and/or sister(s)				
Partner, boyfriend or girlfriend				
Child(ren)				
Other family members				
Emotional				
Sadness				
Feeling alone or isolated				
Anxiety or fear				
Guilt				
Boredom				
Anger or frustration				
Extreme moodiness				
Feeling hopeless or helpless				
Feeling confused				
Loss of meaning or purpose				
Loss of faith or spirituality				
Social				
Isolated from friends				
Missing important events				
Friends don't understand				
Worry about boy/girlfriend				
Missing doing the "normal stuff" with friends				

Rating: L: low concern M: medium concern H: high concern *UR: urgent response
Intervention codes: A: assessment R: referral I: information provision RA: risk assessment ATM: AYA team management

Issue (cross out those not indicated)	Rating	Code	What we are going to do	Contact (name & number)
Physical				
General appearance				
Hair loss				
Breathing difficulty				
Fitness or sporting ability				
Sleeping difficulty				
Constipation or diarrhoea				
Sexual concerns				
Loss of libido (desire for sex)				
Pain when having sex				
Fertility				
Eating or appetite				
Extreme exhaustion or tiredness				
Memory or concentration				
Tingling in hands or feet				
Pain				
Nausea or vomiting				
High temperature or fever				
Use of alcohol and/or drugs				
Other medical worry				
Information				
Understanding of information				
Feeling involved in decision making				
Feeling listened to (eg. by doctors, nurses, family)				
Rights to confidentiality				
Rights to privacy				
Other areas of concern				

Additional comments

I, _____ understand the above care plan and acknowledge that I have been involved in the plan's development. I will try my best to comply with this plan and the recommendations from my treating team.
(Patient's name)

Patient Signature: _____ Date: _____

Clinician Signature: _____ Date: _____

Topic	Notes	Alerts (Risk or Protective)
<p>Family</p> <p>Genogram Where do you live? Who lives at home with you? Is everyone healthy (physically & emotionally)? Are there any new people living in your home? What are the rules like in your home? Is there any violence in your house? What kind of expectations do your parents have about you? How do you get along with your siblings? Who in your family are you able to talk with about things?</p>		
<p>Education</p> <p>What school/Uni/TAFE do/did you go to? What do/did you like best and least about school/studies? What were your most recent grades? Have these changed recently? Have you ever failed, repeated, or skipped school years? How much school/study have you missed over the past 3 months? How do or did you get along with your teachers/tutors? Have you ever had to put up with bullying? How has your school/Uni/TAFE responded to the news of your diagnosis?</p>		
<p>Employment</p> <p>Are you currently employed? Have you recently been employed? What do/did you do? How many hours do/did you work a week? What kind of jobs have you done previously? What kind of work do you hope to do in the future? How has your workplace responded to your diagnosis?</p>		

Topic	Notes	Alerts (Risk or Protective)
<p>Social History (Activities)</p> <p>What do you do for fun? What things do you do with your friends? Tell me about your closest friends? Do you spend time with your family? Do you do any regular sports? Are you a member of any groups or clubs? What kind of TV do you watch? Do you read for fun? Do you use the internet for fun?</p>		
<p>Habits (Alcohol and Drugs)</p> <p>Have you or your friends ever tried alcohol or drugs? What have you tried? How much and how often? Have you done anything that you now regret? Have you ever used a needle? Does anyone in your family drink, smoke or use drugs?</p>		
<p>Relationship and Dating History (Sexuality)</p> <p>Are you involved in a relationship? Have you been involved in a relationship? How was the experience for you? How do you see yourself in terms of sexual preference (i.e. gay, straight, bisexual)? Have you had sex? Was it a good experience? Are you comfortable with sexual activity? Do you use contraception? Have you ever had an experience in the past where someone did something to you that you did not feel comfortable with or that made you feel disrespected? If someone abused you, who would you talk to about this? Has your oncologist, or other health professional, discussed with you about having sex while on treatment?</p>		

Topic	Notes	Alerts (Risk or Protective)
<p>Religious or Spiritual Beliefs</p> <p>Has your cancer led you to search for meaning in life or meaning in this experience? Have you done any other spiritual exploring? Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stressful experiences? What importance does faith or belief have in your life? Are you part of a spiritual or religious community? How has your diagnosis impacted upon your spiritual beliefs?</p>		
<p>Mental Health Status (Suicide / Depression)</p> <p>How do you feel in yourself at the moment on a scale of 1 to 10? Do you ever have really good/bad times? What sort of things do you do if you are feeling sad, angry, or hurt? Is there anyone you can talk to about these things? Do you feel this way often? Have you ever felt like hurting yourself? Have you ever tried to hurt yourself? How strong are these feelings at the moment? Do you have a plan?</p>		
<p>Current Stressors</p> <p>With everything that is going on in your life at the moment, what is creating the greatest stress for you? What about your cancer experience is the most worrying? What is it outside of your cancer experience that is creating the greatest stress?</p>		



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

www.youthcancer.com.au

