

WA Child and Youth Health Network

Paediatric Chronic Diseases Transition Framework

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Government of **Western Australia**
Department of **Health**

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Executive Summary

The Transition Framework for youth to adult services has been developed by the Western Australian Child and Youth Health Network's Paediatric and Adolescent Chronic Diseases Transitional Care Working Party.

There are current and previous health care professionals across Western Australia who have worked to improve transition for specific patient groups. This Framework extends prior work and provides a new focus on improving the transition of young people with chronic disease and disability from paediatric to adult care.

Background

Transition from children's to adult health services is, and will continue to be, an important issue. For many chronic illnesses detected in childhood, care and therapy will continue throughout life and young people will need to be transferred from a paediatric to an adult setting.

Additionally, children are now surviving into adult life with conditions which previously would have been lethal in early childhood.¹ Many of these are rare and obscure and until recently, have been unfamiliar to those predominately working in adult practice.

Failure to ensure satisfactory transition from paediatric to adult services is known to be associated with poor treatment adherence by young people with chronic diseases and disabilities, and subsequent poorer outcomes and increased service costs.²⁻⁴

There are vulnerable groups requiring specialised support and access to services. Amongst them are young people who are Aboriginal, Culturally and Linguistically Diverse (CaLD), socially and economically disadvantaged, those living in residential care, homeless and transient, those that have an intellectual or physical disability and those living under statutory care and protection legislation through the Department for Child Protection. The framework recognises that appropriate specialist liaison and intervention services need to be identified and strengthened for these vulnerable groups to improve access and to ensure successful engagement with adult services.

The framework's intention is to enhance recognition of the need for a transition process and to guide stakeholders when considering transition of young people from paediatric to adult health care services.

Transition Framework Stakeholders

Central to this framework is the continued support of transitional care stakeholders in Western Australia including:

- Consumers, being patients and their family/carers
- Clinicians:
 - Paediatric
 - Adult
 - Primary Care and General Practice
 - Community and Support Care
- Area Health Service planners and designers
- Policy makers, funders and providers
- Other government and non-government agencies and support providers

Guiding Principles

This framework aligns with 'Our Children Our Future-A framework for Child and Youth Health Services in WA 2008-2012'.⁵ The following principles are intended to guide key stakeholders in improving transitional care of young people across Western Australia.

- Planned and coordinated care
- Readiness for transition
- Ownership of transition by the young adult when possible
- Shared responsibility by all involved in the transition
- Accessibility and availability of appropriate services

Objectives

The following objectives will reduce the likelihood of adverse health outcomes whilst meeting the expectations of the patient, their family and the transition team.

- Improve transition planning and preparation
- Tailor transition and appropriately address individual adolescent developmental issues
- Improve communication, coordination and collaboration between service providers
- Improve education and training of health care professionals around transitional care
- Improve patient self management through development of resource information
- Determine, measure and evaluate outcomes.

A range of strategies are identified in the framework for potential application to promote effective transition.

Recommendation

We recommend that this transition framework document be endorsed by WA Health and adopted by Area Health Services and health care providers to improve the transition process for our young people.



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1. Introduction

Adolescence is a period of significant change for any young person and is made even more challenging by ongoing health problems requiring continued care into adulthood. For most young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation.

For young people who are sick or disabled, this transition is made more complicated and difficult by concerns about whether their health and social care needs will be met.⁶ In this group of young people there are individuals with intellectual disabilities and/or limited decision making capacity that will require special consideration.

Current evidence suggests that health outcomes for young people aged 16-24 years are not improving as they are for other age groups. There are also increasing groups of adolescents and young people growing up with chronic diseases of childhood, many of whom fail to engage fully, or at all, with adult services where they exist.⁷ These issues apply equally to mental health as to physical illness.⁸

This drop out from specialist care means that these young people are more likely to re-present in early adult life with preventable illness-related complications, due to sub-optimal self-management.²⁻⁴ Poorly managed transition can lead to additional long term costs to health services, preventable co-morbidities and reduced productivity and life expectancy and social costs such as the cost of suffering and distress on carers and families. The manner in which the young person is transferred to the adult healthcare system is crucial to their continued wellbeing and willingness to engage with ongoing health support and treatment.⁹

Historically, transition to adult services has been regarded as a matter for children's services. This is no longer the case. Children are now surviving into adulthood with conditions from which they would previously have died in childhood or adolescence. It is therefore important for adult services to be engaged much earlier in planning for the transfer of care so that the young person and the services required are properly prepared. Engaging General Practitioners and adult health services at an appropriate time according to individual needs is essential to ensure appropriate services are provided.⁹

1.1 Definition

The plight of young people and their health care transition needs was first recognised during the 1980s in the United States of America.^{10, 11} Reiss and Gibson referred to several policy statements, position papers, and committee reports on transitioning that acknowledged the importance of a planned and orderly transition to adult systems.¹²

The concept of simply transferring a patient from paediatric to adult care in a single step at a point in time has been replaced with the concept of a process of transition, emphasising the need for the change to be guided, educational and therapeutic rather than an administrative event.^{13, 14}

The most useful and often cited definition for transition comes from the American Society for Adolescent Medicine:

“The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems”.¹¹

1.2 Need for a Transition Framework

Why is transition important?

The way in which young people move from paediatric to adult health services is important because it influences the pattern of integration into the adult service and adherence to treatment.^{3, 15-19} In turn, health outcomes are affected and sometimes irrevocably compromised when transition does not occur successfully. The best evidence of this comes from chronic diseases where careful adherence to treatment has a readily measurable effect on outcomes. For young people with diabetes mellitus, cystic fibrosis, congenital heart disease and renal and liver transplantation there is evidence that poor transition results in poor health outcomes.^{1, 3, 4, 20-23} There is also evidence, of varying quality, which indicates that transition influences outcomes in most medical disciplines.²²

Current Situation

Many young people feel vague about the transition process because they have not been given the opportunity to discuss it and participate in decisions and families report that they are faced with a cliff edge where services fall away when the young person reaches the age of 16 years.²⁴

Paediatric and adult health services frequently fail to meet the needs of young people with chronic illness and disability as they move from one service to another. These young people sit poorly between the family-centred paediatric model which frequently ignores the growing independence of the adolescent, and the adult medical model which acknowledges patient autonomy but may neglect growth, physical and psychological development and the social and psychological concerns of the adolescent^{9, 24}. Physicians trained in Adult Medicine may have limited exposure to chronic childhood disorders that now see children surviving into adulthood.

In addition to this, the period of adolescence and the point of transition can be a time when adult type mental illnesses are often first becoming manifest.

Access to services is varied within the metropolitan and rural areas of Western Australia leading to inequalities in patient experiences and overall health outcomes.

“The experience of moving from Princess Margaret Hospital for Children to various adult hospitals was a very stressful experience for me and my family. Going from a hospital where every need was met, to being faced with so many barriers felt terrible and as a highly dependent, depressed and suicidal adolescent I felt lost in a world that was scary and frightening. The stress on my family was immense and to this day I still feel this should not have happened” (*Consumer*)

International and national guidelines

Although international guidelines exist,^{9, 18, 24} in Australia the states are separately developing guidelines for transitional care.²⁵ Although a national approach to transitional care does not yet exist, it is generally accepted that key elements of health care transition processes are developed and adopted in regional and disease specific guidelines.

In Western Australia implementation of transition principles into models of care currently being developed by the Health Networks should contribute to a decrease in the number of adolescents and young people who drop out of services and increase positive health outcomes.

Changes in roles during transition

The process of transition involves significant change for all parties involved. For the young person with a chronic illness it means learning about their condition and beginning the journey towards self-management; for the parents of the young person it means beginning to let go and allowing the young person to begin independent decision making about their condition. For paediatric health care professionals it means acknowledging the young person's growing autonomy and starting to interact directly with the young person rather than exclusively through their parent/s. For adult health care professionals it means developing flexibility in the ways in which services are provided and recognising that the needs of young persons will be different from most other adult groups²⁶

“Lack of being prepared by my hospital to transition into the adult health system was a challenge. An adolescent is not able to immediately take on being responsible for knowing all the details and every facet of the care received over a long period of time. Their parents or carer has always had the control. The adult systems assume the adolescent will have all the knowledge.” (*Consumer*)

Individuals more susceptible to problems during transition

There are a number of groups of young people and their families for whom transition is a potential threat, and who need special consideration in the planning and provision of services. Young people with neurological disorders and chronic disability are often perceived to be at a disadvantage in moving from paediatric to adult services because they have complex needs and have learnt how to manage a system to meet these.^{18, 19} There is often an economic disincentive to move services because of increased costs families can face in the adult sector. The challenges for families are especially great when their young person has an intellectual disability and is dependent upon carers for decision making, advocacy and negotiation. However, neither they nor their health professionals may readily recognise this. Health services may not automatically recognise and respond to the additional demand that such patients can place upon resources.

Transition during palliative care

Some young people with chronic illness and disability need to transition into adult palliative care services.²⁷ This will include individuals with life limiting and life threatening conditions including severe and complex neuro-disability, metabolic disorders and respiratory failure. Some will have been receiving paediatric palliative care prior to transition which may make the transition process smooth, but others will not and the transition process will be especially stressful for them and their families. Thus, the importance of increasing the knowledge and awareness of the conditions which lead into the need for palliative care in adult care settings is vital.

The Transition Framework

The guiding principles of this framework are intended to highlight the dynamic process of transition and the importance of maintaining a patient-centred approach that also recognises the shifting role of the parent/s and health care professionals throughout.

The objectives highlight key priorities along the transitional care continuum, where a range of strategies and recommendations can direct focus towards effective transition. They are to ensure that care is planned, accessible, coordinated and continuous, as well as developmentally and psychologically appropriate. This will therefore reduce the likelihood of adverse health outcomes whilst meeting the needs and expectations of the young person and their family.

1.3 Contributing Literature

The framework is based on key local, national and international literature, as well as evidence based best practices and guidelines in transitioning young people from paediatric to adult health services. Key documents that informed the Framework include:

- UK Department of Health 'Transition: Moving on Well' (2008)²⁴
- UK Department of Health 'Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services' (2006)⁹
- 'Sweet' Diabetes Transition Program Best Practice Guidelines for Health Professionals for the Effective Transition of Young People with a Chronic Illness from Paediatric to Adult Care (2008)²⁶
- Diabetes Australia 'National Review of Transition Care' (2007)²⁸
- Greater Metropolitan Clinical Taskforce (NSW) 'GMCT Transition Care for Young People with Chronic Illness/Disability Service Plan 2007 – 2010'²⁵
- Royal Australasian College of Physicians 'Transition to Adult Health Services for Adolescents with Chronic Conditions' (2006)¹⁴
- Royal College of Nursing (UK) 'Adolescent Transition Care – Guidance for Nursing Staff' (2004)²⁹

2. The Framework

2.1 Aim

The aim of this framework is to ensure that the care to all young people with chronic disease or disability in transition from paediatric to adult health services across Western Australia is planned, accessible, coordinated and continuous, as well as developmentally and psychologically appropriate, thus reducing the likelihood of adverse health outcomes whilst meeting the expectations of the young person, their family and the transition team.

This framework is not intended to educate health care professionals on the clinical management of young people with a chronic disease or disability, but rather is intended to highlight transitional care in Western Australia as a priority for improving the overall health and wellbeing of our children and young people.

2.2 Guiding Principles

This framework aligns with “Our Children Our Future-A framework for Child and Youth Health Services in WA 2008-2012.”⁵ The following principles are intended to guide key stakeholders in improving transitional care of young people across Western Australia.

Principle 1	Planned and Coordinated Care
Principle 2	Readiness for Transition
Principle 3	Ownership of Transition by the Young Person
Principle 4	Shared Responsibility by all Involved in the Transition
Principle 5	Accessibility and availability of services

Principle 1

2.2.1 Planned and Coordinated Care

Transition from paediatric to adult health care services should be carefully planned and should start early, with coordination between health care providers throughout. It should also be clear to a young person, parents and professionals what the process involves, who is involved, what steps need to be taken along the way and by whom.

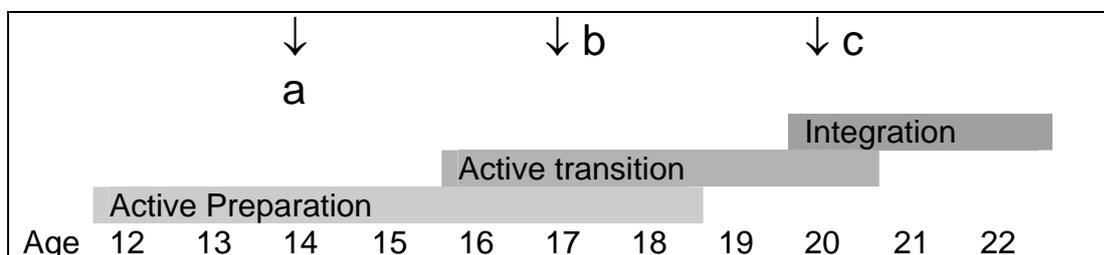
Transition should be commenced at the onset of the chronic disease or disability, with planning for actual transition to begin in earnest in early teenage years. The process should be planned as an integral part of the long term management plan for the young person's medical treatment and employ strategies to empower the individual.

“Our son has global developmental delay, autism spectrum disorder, epilepsy and extremely challenging behaviours. Mostly, he was well supported by the paediatric health services from birth. Unfortunately, despite ongoing medical needs and high doses of multiple medications, there had been no transition planning for him for medical services within the adult health system.” (Mother of 20yr son)

Health Care Transition Phases

Health care transition is generally recognised to consist of three stages; preparation phase, active transition phase and integration phase³⁰ (See Fig 1).

Figure 1. Health Care Transition Phases³⁰



↓ = Potential stages for use of health care transition readiness measure

Active Preparation

The active preparation phase serves to introduce the young person and their family to the concept and importance of transitioning and usually starts when the young person is between twelve and fourteen years of age. The focus of this phase is on education and support. For this phase a readiness measure can be used to guide interventions for recommended two-year minimum preparation phase. Assessment of transition readiness, rather than age, is an important precursor to implementing transition services.^{31 32} It is important to identify deficits that need to be addressed before transition actually occurs.

Active Transition

The active transition phase involves the actual transfer of care from the paediatric setting to adult health care when the individual reaches psychosocial readiness rather than a set age. It is important that this phase occurs during a period of stability in the young person's life.

Integration

The move to adult health signals the start of the final integration phase. Paediatric health services need to ensure engagement by the young person with adult services before paediatric services cease. This change also signifies a shift in philosophy, a shift from family centred care to individualized healthcare.

The young person must have the necessary cognitive abilities to be able to take responsibility for their health needs, tasks and decisions that previously had been made either solely by or in consultation with their parents. In order for this phase of transition to be successful, the young person requires adequate education, support and empowerment combined with knowledge of, and an ability to negotiate, the adult health care system and their own healthcare needs.

Young people lacking cognitive abilities will require ongoing support and assistance with education and decision making from parents and/or carers to ensure transition is successful.¹⁹

Principle 2

2.2.2 Readiness for Transition

For all young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation. This will occur at different times and at a different pace for all young people. Sick or disabled young people find this transition even more complex and difficult due to concerns about how and where their health and social care needs will be met. Many young people feel vague about the transition process as they may not have been given the opportunity to discuss it and participate in decisions. Families report that they are faced with a cliff edge where services fall away when the young person reaches the age of 16 years.⁹ This is especially true for those families who have a young person with a chronic neuro-disability and require multiple components of care, and are faced with re-negotiation of each element of care with multiple professionals and services.¹⁸

When a young person is ready, successful transition requires them, their parents/carers and health care professionals to understand the process of normal adolescent development, the impact of risk-taking behaviours, and the impact of chronic illness on normal adolescent development and social relationships.

Accordingly, paediatric health care professionals must allow children to grow up and parents to let go, whilst adult health care professionals and general practitioners alike must not expect young people to always behave as mature adults. Young people have different priorities, do not always think like mature adults and may have limited capacity to fully understand the long-term consequences of particular behaviours and to plan for the future. It is also vital that health care professionals and parent/s alike recognise the need for young people to be equipped with appropriate and adequate knowledge in order to be able to self manage and flourish into adult life.

Special consideration (which may include legal assistance) may be necessary for the parent/s of young people who are cognitively impaired, to enable appropriate proxy decision-making to occur in the best interest of the young person.¹⁸

Principle 3

2.2.3 Ownership of Transition by the Young Adult

A young person needs preparation and appropriate support to take ownership of, and responsibility for their health condition, care requirements and engagement with health professionals. Parents will need to let go by offering support and security for the young person to explore and practice away from parental supervision and enabling them to progress safely to autonomy. This may include making different decisions from their parents and at times seeking out health care professionals and services that meet their individual needs. As previously discussed ownership of transition will be especially problematic for some individuals with an intellectual disability and/or limited decision-making capacity, who will require specialised assessment, intervention and flexibility from all parties.

Principle 4

2.2.4 Shared Responsibility by All Involved in Transition

Although transition to adult health care has traditionally been seen as a matter for children's services, it is important that this view change. As children are surviving longer into adulthood with conditions that once they would have died from, it is important for adult and primary care health services to be engaged much earlier in the planning and transfer of care, so that both the young person and the service are properly prepared.^{9, 24} Increasingly, training in adolescent medicine is accessed by both adult and paediatric medicine programs.

Partnerships between paediatric and adult specialist health services, primary health carers, school and community health care professionals, patients and their parent/s are needed to ensure a collaborative and consistent approach to transition. The parents/carers of young people with intellectual disabilities and/or limited decision making capacity will retain a greater role in the partnership than parents of other young people.

General practitioners have special roles in this process, and need to participate regularly in the planning and implementation of transition plans. This may be challenging in dealing with families used to dealing with specialists who may not regularly include general practitioners in the interactions.³³ The general practitioner will however have opportunity to reinforce aspects of transition planning and to maintain interaction with the young person over a longer time period. They will inevitably fulfil roles of both paediatric and adult services.³⁴

Principle 5

2.2.5 Accessibility and Availability of Services

Limited access to and availability of health care services in meeting the needs of transition is a result of failure of recognition of need, geographical service planning and design and resource allocation.

The health needs of young people are often poorly met, because they do not comfortably fit anywhere, with services tending to split along the paediatric or adult divide.⁸ Youth friendly services are required in all health settings.

Young people in rural and remote areas of Western Australia have limited access to specialist services and the expectation that once transitioned, patients will access some adult services in the metropolitan area, are examples of key issues requiring urgent attention.

There are other vulnerable groups requiring specialised support and access to services. Amongst them are young people who are Aboriginal, Culturally and Linguistically Diverse (CaLD), socially and economically disadvantaged, living in residential care, homeless and transient, have an intellectual disability, are involved with the Justice and/or Police Departments, and living under statutory care and protection legislation through the Department for Child Protection. Appropriate specialist liaison and intervention services need to be identified and strengthened for these vulnerable groups to improve access and to ensure successful engagement with adult services.

A further challenge is the presence of adverse psychosocial factors. These include mental illness (young person and/or parent), child abuse, homelessness, teenage pregnancy, drug and alcohol use and risk-taking behaviours that may restrict a young person's ability to access and engage successfully with transitional care services.

Hence, ensuring services are accessible and appropriate is viewed within the framework as integral for improving transitional care experiences and outcomes for all Western Australians. This has been given particular attention since strategies to improve service planning and design will not necessarily reduce health inequalities.

2.3 Objectives

Objectives within this framework highlight priorities along the transitional care continuum, and aim to ensure the care of all patients in transition to adult health services across Western Australia is planned, accessible, coordinated, continuous and developmentally and psychologically appropriate thus reducing the likelihood of adverse health outcomes whilst meeting the expectations of the patient, their family and the transition team.

Objective 1	Improve transition planning and preparation
Objective 2	Tailor transition and appropriately address individual adolescent developmental issues
Objective 3	Improve communication, coordination and collaboration between service providers
Objective 4	Improve education and training of health care professionals around transitional care
Objective 5	Improve patient self management through development of resource information
Objective 6	Determine, measure and evaluate outcomes

Objective 1

2.3.1 Improve transition planning and preparation

Evidence of the benefits of planned transition is now emerging and a smooth transition can improve quality of life for young people with chronic and complex health needs and disabilities.^{4, 20}

Planning that puts the young person at the centre of the process will prepare them and their family for the move to adulthood and the transfer to adult healthcare. Early engagement with adult health services and continuing active

links with the general practitioner reduces the risk of over-dependence on comprehensive children's services as young people and families move on from the child focussed model.³⁴

Transition to adulthood requires consideration and negotiation in relation to all aspects of the young person's life including higher education, vocation and training, leisure, self-care, relationships, independence and where they wish to live. While negotiating these issues attention also needs to be given to successful transition to adult health care. This requires the young person, parents/carers and health care professionals to understand the process of normal adolescent development, the impact of chronic illness on normal adolescent development and relationships and the impact on their health due to risk-taking behaviours. Mental illness can be characterised by stigma and shame for young people, therefore willingness to continue treatment can be limited. It is estimated that 25% of young people with mental illness access professional help³⁵ therefore these issues must also be addressed.

Health professionals in partnership with families can contribute to preparing a young person for adulthood by developing a health transition plan. This takes an approach that is much broader than the medical diagnosis and helps the young person to develop the necessary knowledge and skills to empower and enable them to cope with the responsibilities of taking charge, not only of their condition, but other important lifestyle issues that may be concerning them.²⁴ An example of a Transition Self Management Checklist is outlined in Appendix 3.³⁶ Some groups have recommended detailed assessment of readiness utilising tools that reflect the stages of behaviour change.

Successful planning should be patient centred and dynamic, recognising that the young person's needs may change over time. It may be a simple or complex process depending on the young person's condition, social circumstances and the range of services required.²⁴ The young person with complex neuro-developmental disability may require comprehensive case management, undertaken with parents/carers to achieve effective transition planning and ongoing care. The special needs of Aboriginal young people need to be considered and planned for given their much higher rates of long term dropout from health services, morbidity and mortality.³⁷

2.3.1 Strategies to improve transition planning and preparation

- Begin transition planning as early as possible, ideally at diagnosis or during early childhood, with transition in earnest beginning by age 13 years.
- Educate parents and the young person regarding the transition process.
- Identify specific cultural, social, religious and spiritual requirements around transition.
- Involve the general practitioner early in regular follow-up of all children with chronic disease and disability.
- Involve Aboriginal medical services and community health teams early in regular follow-up of all children with chronic disease and disability and in transition planning.
- Develop clear transition pathways (Appendix 1) for different diseases and conditions outlining the roles and responsibilities of those involved before, during and beyond transition.

- Develop Transition Readiness Kits for assessment of a young person's ability to manage transition, and to identify issues that need work. (An example is given in Appendix 2).
- Raise clinical service awareness of the need for early transition planning, for example, through the use of posters and reminders for outpatient clinics.
- Start to see cognitively able young people on their own, for part of the consultation from about the age of 12 years.
- Ensure sufficient, appropriate and flexible clinic times are considered when planning services including availability of longer consultations and appropriate privacy and appropriate clinical areas for young people (ie not areas shared with infants, young children and senior citizens).
- Review physical infrastructure of services and assess suitability for young people.
- Appoint dedicated adolescent transition coordinators across hospitals and Area Health Services.
- Appoint dedicated adolescent disability transition coordinators across hospitals and Area Health Services to deal with complex neuro-developmental care.

Objective 2

2.3.2 Tailor transition

In order to appropriately and effectively facilitate the transition of young people with chronic disease or disability from paediatric to adult health care, it is essential to understand adolescent development, behaviour and health issues. It is also vital to acknowledge the different time at which each individual will enter the transition process and the different pace in which they will progress through it. An understanding of these factors and the changing role of the parents will influence the young person's ability and willingness to engage with new services.^{30, 38}

It is not appropriate to assume that young people will view adult services as ideal or accessible. Having to mix in a clinic with other patients of a very different age group, the location of a clinic within a very large hospital, lack of flexibility regarding appointment times or a physical environment that is not teen friendly can prove intimidating and inhibit clinic attendance and adherence to treatment.

Young people with neuro-developmental and significant behavioural difficulties may not have access to diagnosis specific clinics in adult settings. Families are then confronted with issues such as medication and therapy in environments which are not friendly or supportive to this cohort. They will require special consideration because of their dependence upon a range of health and other external services. These young people are especially likely to drop out of care if they are unable to maintain connection with paediatric health service providers, ostensibly because of difficulty in achieving recognition of their special needs.^{18, 39} The issues cited by parents include failure of recognition of impaired decision making ability and the need for other advocates to participate in decision making, failure of recognition of the physical and economic burdens that families bear in dealing with these young people, and inflexibility of large organisations.

“Earlier this year, due to escalating life threatening self injurious behaviours and aggression towards others, our son needed immediate medical intervention. It was apparent that the only option available to us was admission through an Emergency Department. The experience proved to be very traumatic for all involved – it was obvious that he did not fit into the system due to, amongst many issues, his disabilities. Eventually, after much angst, he was admitted to an adult psychiatric ward. It was instantly obvious that few staff had the training or experience to deal with the complexities of a person with cognitive delay, autism and challenging behaviours – mostly the staff were very supportive, but many could not, or would not, follow the required Behaviour Management Programme (BMP). Caring for our son is by no means an easy task; it requires responses that are totally counter intuitive but, combined with medication, adhering to his BMP is the only pathway for him to become stable enough for discharge. The transition process to adult services has been traumatic and exhausting and we still have a very long way to go. However, we are relieved and appreciative that, after this long and confusing battle, someone had taken responsibility for managing the multiple medications, acknowledged that our son has mental health issues and that there are periods when he need to be hospitalised for medication review and/or his own and others safety. We have some very special people working in our health sector and we need to support them, and those they care for, in every way possible.” (*Mother of 20yr son*)

Young people with life limiting illnesses, including those receiving palliative care, will require specific services and individualised care plans. The elements of these care plans will need to include a coordinated approach and include end of life decision planning. Some of these people may not need to access all health care disciplines offered, however transition still needs to be coordinated and holistic.

The framework recognises the need to improve current approaches to transitional care information and education and to tailor a transition process that aims to address each individual’s unique issues, including their readiness and risks of engaging in adverse health-related behaviours.

2.3.2 Strategies to tailor transition

- Identify a culturally appropriate key health professional for each young person who will assist them and the health team/s to plan and negotiate transition.
- Explore with young people opportunities for developing skills in managing their condition/s, improving their self-image and maintaining good mental health and wellbeing.
- Evaluate, educate and review young people’s lifestyle factors including mental health co-morbidities, sleep and activity, alcohol and drug use and their interplay on the course of the disease.
- Review adolescent clinic appointment availability, flexibility and means of contact to accommodate young people’s lifestyles, education and employment.
- Develop a young person’s assessment tool to identify key issues in readiness for transition (Appendix 3).

- Encourage young people to familiarise themselves with their medical history by completing their own medical history summary (Appendix 4).
- Establish telephone and drop in support services.
- Prepare and support parents for a change in role as they assist their young person through transition.
- Develop a resource kit and a tailored education program for the young person prior to them leaving the adolescent service.

Objective 3

2.3.3 Improve communication, coordination and collaboration

The framework recognises the experiences and overall outcomes of young people in transition from paediatric to adult health care. In order to improve the experience and outcomes, attention must be focussed on improving the quality of transitional health care service delivery.

Health care professionals from both children's and adult health care services are well placed to support transition to adult care. Child health care professionals are the first to be involved with a baby or young child with a chronic disease or disability and can help ensure that choice, self-management and independence are already familiar concepts to families by the time they become young people. Conversely, the fact that paediatricians are involved early on with babies and young children may act as a barrier to effective transition as they may continue to treat the emerging adolescent as a young child.

In many instances, the young person and their family are well known to staff within children's health services. Relationships based on trust will have developed over many years. This makes the transition to adult care all the more daunting, particularly if the child's condition has required frequent intervention or if the young person's condition is rarely seen in adult services. A reluctance of paediatric services to let go, can be a deterrent to families wanting to transition and be a barrier to engagement with adult services.

Traditionally, a lack of a shared care approach by paediatric services has excluded greater involvement of adult health care professionals and general practitioners. This has meant a reduction in their skills and confidence to be involved in the care of rare paediatric conditions, adolescence and particularly transition. This type of comprehensive one-stop shop paediatric care is highly beneficial until transition but limits the general practitioner's role.

For transition to be really successful it is important that general practitioners and adult health care services are closely engaged in preparing the young person for the eventual transfer of their care. As indicated above the general practitioner should be engaged early, and supported in taking a greater role in routine care of children with chronic illness.³⁴ This role becomes especially important when young people fail to immediately engage adult services.²⁶

Current issues and barriers to effective communication and coordination between health care service providers involved in transition across Western Australia include, but are not limited to:

- Lack of adequate engagement of general practitioners in the long term care of children with chronic, complex disorders.

- Lack of a consistent and efficient handover process from paediatric to adult services.
- Lack of recognition of adolescent health as a specialty area within university, undergraduate and postgraduate health care courses and by health professionals in general.
- Lack of appropriate adult services for some conditions.
- Lack of awareness of and/or training in adolescent health for paediatric and adult health care professionals.
- Lack of flexible multidisciplinary and shared care approaches to service delivery, including scheduling of appointments.
- Inequalities in staffing resources between paediatric and adult services and metropolitan and rural areas.
- Poor decision support for staff, especially for adult health care professionals and general practitioners.
- Lack of support and training in transition for general practitioners.
- Significant changes (reduction) in funding options and services for young people over school age.
- Variations in supply of material resources (medication and equipment) between different services.

2.3.3 Strategies to improve communication, coordination and collaboration

- Collaborate with key stakeholders to strengthen and further develop partnerships among paediatric, adult and primary health care providers especially in disease specific areas.
- Provide training and education on communicating with young people as part of university higher education degrees and in continuing professional education courses/seminars.
- Support development of integrated care pathways to identify who should do what, when, and where, taking into account the organisation of the health care delivery process as experienced by the patient.
- Develop a transition discharge summary tool to identify key issues for long term follow up by the general practitioner and specialist services.
- Develop a personally held medical record to facilitate continuity of care and ownership by the young person of their health condition and care plans, which must identify care with a general practitioner.
- Create Transition Care Coordinators for each Area Health Service.
- Develop specialised services for vulnerable groups such as Aboriginal, CaLD and disadvantaged groups to ensure their needs are continually met.
- Appoint dedicated adolescent disability transition coordinators across hospitals and Area Health Services to deal with complex neuro developmental care.
- Initiate joint Adult-Paediatric Transition Clinics in those areas where there is a large number of young people with a particular disease (eg diabetes mellitus, juvenile idiopathic arthritis, cystic fibrosis).
- Promote youth friendly services within adult settings including a secure environment allowing interaction with young adults only, young adult friendly areas in adult hospitals.

- Ensure the use of interpreters and culturally appropriate and language specific translations of relevant documents.
- Educate health professionals outside of public sector health services regarding Medicare Benefits Schedule item numbers which facilitate longer consultation and the coordination and case management often required in caring for young people with chronic, complex disorders (Appendix 6).
- Develop a state-wide approach to chronic illness data management through the Health Networks.
- Educate families about the difference between services in relation to provision of material resources (medication and equipment).

Objective 4

2.3.4 Improve education and training of health care professionals

The delivery of high-quality health services requires a highly skilled and knowledgeable workforce. The importance of addressing workforce issues and the need to enhance and sustain the current level of quality of the WA Health workforce has been detailed in the WA Health *Healthy Workforce Strategic Framework 2006-2016*,⁴⁰ and should be referred to in conjunction with this framework.

The specialist nature of paediatric health care services necessitates continued post-graduate education and training of health staff. Maintaining skills to increase the effectiveness and efficiency of the health workforce will allow delivery of innovative programs and treatment. Hence there is a clear recognition in the *Healthy Workforce Strategic Framework 2006-2016* of the need to invest in workforce development and training and developing partnerships with the higher education and vocational education and training systems to promote flexibility in education and training.

The major education and training issues affecting transitional care health service providers in Western Australia include, but are not limited to:

- Few senior health care professionals with experience in the management and transition of complex young adults.
- A lack of knowledge of some health care professionals of paediatric onset chronic diseases and disabilities, adolescent development and the impact of disease on the adolescent and youth.
- Limited mobility of the health service population, limiting development of specific expertise with adolescents and complex cases.
- Limited opportunities and availability of education and mentoring programs for health care professionals and students involved with transition or young adult care.
- Limited involvement of general practitioners leading to them becoming a bystander, and hence they may be deterred by the needs of complex young adult cases.

2.3.4 Strategies to improve education and training of health care professionals

- Increase emphasis on adolescent health and transition in undergraduate and postgraduate health professional and social care curricula, within higher education across Western Australia and nationally with the professional colleges.
- Provide clinical education, mentoring and training for all health care professionals regarding adolescent issues and treatment.
- Encourage paediatric and adult health professionals to develop specific expertise in adolescent health.
- Develop and supply information packs to paediatric, adult and primary health care professionals on adolescent transitional care, communication and care provision issues such as HEADSS sheet (Appendix 5),
- Recognition and knowledge of mental health issues, health service funding and Medicare billing arrangements that will encourage chronic care (Appendix 6).

Objective 5

2.3.5 Improve patient self management

Self-management is the active participation by people in their own health care. Self-management incorporates health promotion and risk reduction, informed decision making, care planning, medication management and working with health care providers to attain the best possible care plus effectively negotiating the often complex health system rather than being a passive recipient of the process.⁴¹

Support for self-management should be introduced at the earliest opportunity as this enables the young person to adopt self-management behaviours while they remain in a supportive environment. This necessitates a willingness on the part of health professionals and parents to take considered risks in handing over responsibility for important issues to the young person.

Barriers to effective self management include a willingness by young people to accept a compromise in standards and at times sub-optimal care and health outcomes; physical and intellectual disability that limits decision making ability, limited access to information and services because of education, geography or social circumstances.

Often the level of educational material particularly regarding self management is seen as inappropriate by young people and their families as it fails to address the unique challenges of chronic disease and disability management within the context of adolescence and shared decision-making responsibilities.

2.3.5 Strategies to improve patient self management

- Improve and develop resources and education information for individuals, families and carers before, during and beyond the transition process.
- Ensure culturally appropriate and language specific translation of relevant resource information.
- Encourage paediatric health care professionals to foster independence, autonomy and self management amongst young people, whilst supporting parents in letting go where appropriate.

- Improve access to information for young people, their parents and carers on community and support options including equipment, youth services, respite, government allowances and supported accommodation to maintain independence.
- Develop a transition tool kit for young people containing vital information to enhance their efforts towards self management. The tool kit may include information on accessing General Practitioners and adult services, Medicare and billing information, management of appointments, booking ahead before medication runs out, how to deal with work and travel issues for their condition etc.

Objective 6

2.3.6 Determine, measure and evaluate outcomes

While there is accumulating evidence that transition is important, many aspects of best practice require clarification. Reliable and valid generic measures of *Health Care Transition Readiness*, with condition-specific additions need to be developed for use as a diagnostic and remedial tool at the various stages of transition.

Within Western Australia further information is required regarding the increased burden of disease that arises from poor transition.

Knowledge of the effectiveness of the services we provide is important in planning and allocating resources. The issues that determine effectiveness include mortality, morbidity, patient satisfaction, quality of life, waiting times, responsiveness and cost. Key performance indicators need to be established to assess the effectiveness of transition services. In addition longitudinal theoretical studies are required to understand optimal timing of transition, duration of transition co-morbidities which can be modified by lifestyle changes, and young people's description of chronic illness and their psychosocial outcomes.⁴²

2.3.6 Strategies to determine, measure and evaluate outcomes

- Develop a State-wide approach to chronic illness data management.
- Create focus groups to ascertain young people's views on resources, delivery mode, health care needs, etc.
- Develop a transition readiness instrument with illness specific subscales.
- Adopt performance measures to include determination and evaluation of transition data including: availability of teen friendly clinic elements, the number of patients missing appointments and patient satisfaction.
- Record specific objective outcomes (eg FEV1 for cystic fibrosis, HbA1c for diabetes, unscheduled hospital visits for any disease).
- Measure satisfaction of young people with the transition process.
- Measure satisfaction of families and carers of young people with limited intellectual capacity with the transition process.

Appendices

Appendix 1 Internet Links to Transition Pathways

General, NSW

http://www.health.nsw.gov.au/gmct/transition/resources_prof.asp#para_15

General, UK

<http://www.library.nhs.uk/GuidelinesFinder/ViewResource.aspx?resID=67135>

General, Washington State

<http://depts.washington.edu/healthtr/>

Adult Congenital Heart Disease

<http://www.library.nhs.uk/GuidelinesFinder/ViewResource.aspx?resID=125846&tabID=288>

Diabetes

<http://www.sweet.org.au/>



Appendix 2 Diabetes Transition Progress Sheet: example of a work in progress



Government of Western Australia
Department of Health

(affix patient identification label here)

URN

Family name:

Given names:

Draft – not for use

DIABETES TRANSITION PROGRESS SHEET

Facility:

Date of Birth

Sex M F

The purpose of this form is to document the progress of the young person through the transition process from paediatric to adult care. This sheet must be filed in the patient record of the relevant organisation.

A photocopy of this progress sheet should be included with the young person's documentation:

- At time of transfer to an adult service, or
- If transferred to another health service during the transition process.

Starting Transition

Starting date of transition process: _____

Age of young person starting the transition process: _____

DO NOT WRITE IN THIS BINDING MARGIN

DIABETES TRANSITION PROGRESS SHEET

Step 1
12-13yrs

Information

- Has an explanation and written information on the Transition Process been given to:
 - Parents/Carers Yes No
 - Adolescent Yes No
- Has information been given on the sweet.org.au website? Yes No
- Has an estimated age at transfer been discussed with family? Yes No
- If Yes, at what age is the adolescent expected to transfer:.....

Step 1 Completed (sign off when completed)

NamePosition.....SignatureDate.....

Step 2
12-13yrs

Knowledge and Allied Health Assessments

- Has an assessment of diabetes knowledge and education occurred? Yes No
- Has a dietary review occurred? Yes No
- Has a mental health review occurred? Yes No
 - Parents/Carers Yes No
 - Adolescent Yes No

Education to be delivered at this time (tick box when complete)

- | | | |
|---|--|--|
| <input type="checkbox"/> About diabetes | <input type="checkbox"/> Insulin therapy and adjustment | <input type="checkbox"/> Diabetes control |
| <input type="checkbox"/> Management of 'hypos' | <input type="checkbox"/> Diabetes complication screening | <input type="checkbox"/> 'Sick day' management |
| <input type="checkbox"/> Effects of puberty on diabetes | <input type="checkbox"/> School issues and school Camps | <input type="checkbox"/> Exercise |

Comments:.....

Step 2 Completed (sign off when completed)

NamePosition.....SignatureDate.....



Step 3
15yrs

Moving Towards Independence

- 8. Is the adolescent seeing their diabetes doctor alone for part of the visit? Yes No
- 9. Have options for adult care been discussed with the young person? Yes No
- 10. Has a dietary review occurred? Yes No
- 11. Has a mental health review occurred? Yes No

Additional education and information to be delivered at this time (tick box when completed)

- Alcohol and related issues Diabetes and sexuality Feelings and emotions – burnout
- Confidentiality Government allowances 'Smoking and recreational drugs
- What to expect from a medical consultation

Comments:.....

Step 3 Completed (sign off when completed)

NamePosition.....SignatureDate.....

Step 4
16-17yrs

Assigning a Case Manager

- 12. Has a Case Manager been assigned? Yes No
- 13. If Yes, state?

NamePosition.....

Step 4 Completed (sign off when completed)

NamePosition.....SignatureDate.....

Step 5
16-17yrs

Knowledge Assessment

- 14. Re-assess diabetes knowledge and skills? Yes No
- 15. Is general diabetes knowledge as outlined in Step 2 up-to-date? Yes No
- 16. Is knowledge on topics outlined in Step 3 up-to-date? Yes No

Comment(s):

Information and Review

- 17. Discuss health care options and choice of adult provider following transfer
- 18. Dietary review
- 19. Mental health review

Additional information and education to be delivered at this time (tick box when complete)

- Getting a driver's licence Tertiary studies and employment NDSS
- Health care system and costs Obtaining a Medicare Card Travel and diabetes
- Diabetes and 'Schoolies' week.... How to actively participate in a consultation

Comment(s):

Transition Clinic/Visit

- 20. Are joint or alternating visits occurring with the paediatric and adult services? Yes No
- 21. If No, what action will be taken to engage an adult service in this young person's care:

.....

Step 5 Completed (sign off when completed)

NamePosition.....SignatureDate.....



Step 6
18+ yrs

Transfer

The age that the young person finally transfers to an adult diabetes service or clinic will depend on their individual needs and whether there is an adult diabetes service available in their area. Most places transfer young people when they turn 18 years or when they finish school.

Checklist (tick box when completed)

- 22. Prior to transfer re-assess diabetes knowledge and skills
- 23. Address diabetes education deficits
- 24. Arrange dietary review
- 25. Arrange Mental Health review
- 26. Arrange appropriate prescriptions
- 27. Written referral sent to adult service/doctor
- 28. Appointment with adult service/doctor
- 29. Details of adult service/doctor
 Name: Type of service/doctor: Public Private
 Address:
- 30. Appointment:.....Date:..... Time:.....
- 31. Appointment details given to young person
- 32. Discharge Summary complete and sent to adult service/doctor
- 33. Date of transfer:

Step 6 Completed (sign off when completed)

NamePosition.....SignatureDate.....

Step 7
18+ yrs

First Follow-up

Due to the high number of young people lost to diabetes specialist follow-up after transfer, the Case Manager should remain in contact for around 6 months after transfer (minimum of 2 contacts)

- 34. Date of first contact post transfer:
- 35. Is the young person attending an adult service/doctor they were transferred to? Yes No
- 36. If No, please comment:

Subsequent Follow-up

- 37. Subsequent contact date(s):
- 38. Is young person attending adult service/doctor they were transferred to? Yes No
- 39. If No, please comment:

Additional contacts should be recorded in the patient's medical record.

Step 7 Completed (sign off when completed)

NamePosition.....SignatureDate.....



Appendix 3 Transition Self Management Checklist³⁶

Patient Gender: **Male** **Female**
Patient Age: **Date:**

Leave Blank if Not Applicable	Yes	No
Has sound knowledge of medical condition		
Can name and explain medical condition		
Can describe current health status		
Can list medications and other treatments		
Can explain why each treatment is required		
Can discuss potential side effects of each treatment		
Can self manage medical condition		
Can prioritise health over other desires		
Can remember to take medication most of the time		
Can ask questions of health care professionals (HCPs)		
Responds appropriately to questions asked by HCP		
Can consult with HCP without parents in attendance		
Can negotiate health system effectively		
Has own Medicare card		
Can fill a prescription in a timely manner		
Can manage appointment scheduling		
Knows how to contact HCP in an emergency		
Knows how to contact appropriate advocacy group		

General Comments:



Appendix 4 Personal History Sheet

As you make the transition from paediatric to adult health care, you will be assuming more responsibility for your health care. When you go to your new adult services doctor, GP or other health care provider, you will be asked about other major health events in your life. **You may find it helpful to ask a parent or other adult help you fill out this form.** Take it with you when you go to your new adult care doctor (or other health care provider) and you will be prepared for the questions that you will be asked .

How would you describe your overall general health? (Please circle one and add comments if you want to)			
Fair	Good	Excellent	
What are your special health care needs? Is there anything in particular that your doctor needs to know about your special needs?			
As a child and teenager, what were your major health problems?			
What medications are you currently taking?			
Medications:	What is it taken for	How Much (dose)	How often (schedule)



Allergies or adverse reactions to medications:			
there any medications that you have taken that have caused you problems?			
Medication		Reasons for no longer taking medication	
Food or other allergies: (include bee stings)			
Food or substance		Reaction and treatment	
Past medical history:			
Your birth weight		Were you born early?	If so how many weeks early?
Did your mother have any problems with her pregnancy or delivery of you?			
Were you hospitalised at the time of your birth?			
If yes, how many days?		Or weeks?	
What problems did you have at birth?			
Please list any serious illnesses you have had and any injuries that include loss of consciousness.			
Please list hospitalisations and surgeries you have had and include the dates and places.			



Personal health history: Have YOU ever had the following

Condition	Yes	Age	Condition:	Yes	Age
Anaemia			Depression		
Asthma			Suicide attempt		
Blood Transfusion			Conduct Disorder		
Cancer			Anxiety		
Constipation			Learning Disability		
Diabetes			Developmental Delay		
Ear Infections			Eating Disorder		
Eating Problems			Other conditions not listed:		
Heart Disease					
Hepatitis					
Seizures (Epilepsy)					
Tuberculosis					
Attention Deficit Disorder					

If the answer is yes to any of the above conditions please use this space to make any additional comments about the conditions. **For individuals with seizures**, describe the seizures and include how often the seizures occur, how long they last, and when was your last one?

What tests have previously been done for these conditions, what were the results, and where were they done? (MRI? CT? EEG? Genetic Testing? Blood Tests? Psychological Testing?)

What treatments have been tried for these conditions and what was the most successful?

Are the conditions: (please circle one) (the same) (improving) (getting worse)



Resource Information:

School: _____ Grade in School: _____
 Do you have an Individual Education Plan (IEP)? _____ Do you have a 504 plan? _____
 Name of contact person at school _____ Telephone _____
 Do you use Vocational Rehabilitation services? _____ Contact person at VR _____

Recent medical records:

List the name, address, and telephone number of any doctors or other health care providers who have the latest medical records about your health conditions.

Name	Specialty	Address	Telephone #

Other resources:

List the name, address and telephone number of any other person that has worked with you in regard to your health condition in the past two years (such as a physiotherapist, pharmacist, medical supply house, caseworker, school nurse, etc.).

Name	What They Do	Address	Telephone #

Your immunization dates: (Or attach a copy of your immunization record)

DPT/DT	1.	2.	3.	4.	5.
TD	1.	2.	3.	4.	5.
OPV	1.	2.	3.	4.	5.
MMR	1.	2.			
HIB	1.	2.	3.	4.	
Hep B	1.	2.	3.	4.	
Varicella	1.	2.			



Family Health History: have any of your blood relatives had the following:

Condition:	Relation
Anaemia	
Breast Cancer	
Cancer (Other)	
Diabetes	
Heart Attack	
High Blood Pressure	
High Cholesterol	
Seizures	
Sickle Cell Anaemia	
Stroke	
Thyroid Problems	
Tuberculosis	

Condition:	Relation
ADD/ADHD	
Alcoholism	
Depression	
Drug Abuse	
Learning Disability	
Manic Depressive	
Suicide	
Schizophrenia	
Other Conditions?	

Comments:

Insurance Coverage Information:

Insurance	Policy number	Telephone number

Do you receive Centrelink payments)?	YES	NO
Do you have a current health care card?	YES	NO

Emergency Contacts:

Name	Relationship	Telephone numbers
		(W) (H)
		(W) (H)



Activities of Daily Living

	YES	NO
Are you legally blind?		
Do you wear glasses or contacts?		
Are you deaf or hard of hearing?		
Do you use a hearing aid?		
Do you have any speech problems?		
Do you use sign language?		
Is English your preferred language? If no, what language do you speak?		
Can you walk?		
Do you use a walker?		
Do you use a wheelchair?		
Do you routinely wear medic alert identification?		

What other aids do you use to accomplish daily activities?

Are there any restrictions to your daily activities? (Can you drive a vehicle? Do you need a computer to communicate? Etc.)

Your adult doctor will ask you questions in private about your sexuality, drug, alcohol and cigarette use and your mood (anxiety, depression).



Appendix 5 HEADSS For Adolescents

Assessment:

Home

- Who lives with the young person? Where?
- Do they have their own room?
- What are relationships like at home?
- What do parents and relatives do for a living?
- Ever institutionalised? Incarcerated?
- Recent moves? Running away?
- New people in home environment?

Education and employment

- School/grade performance--any recent changes? Any dramatic past changes?
- Favourite subjects--worst subjects? (include grades)
- Any years repeated/classes failed
- Suspension, termination, dropping out?
- Future education/employment plans?
- Any current or past employment?
- Relations with teachers, employers--school, work attendance?

Activities

- On own, with peers (what do you do for fun? where? when?)
- With family?
- Sports--regular exercise?
- Church attendance, clubs, projects?
- Hobbies--other activities?
- Reading for fun--what?
- TV--how much weekly--favourite shows?
- Favourite music?
- Does young person have car, use seat belts?
- History of arrests--acting out--crime?

Drugs

- Use by peers? Use by young person? (include tobacco, alcohol)
- Use by family members? (include tobacco, alcohol)
- Amounts, frequency, patterns of use/abuse, and car use while intoxicated?
- Source--how paid for?



Sexuality

- Orientation?
- Degree and types of sexual experience and acts?
- Number of partners?
- Masturbation? (normalize)
- History of pregnancy/abortion?
- Sexually transmitted diseases--knowledge and prevention? Contraception? Frequency of use?
- Comfort with sexual activity, enjoyment/pleasure obtained? History of sexual/physical abuse?

Suicide/Depression

- Sleep disorders (usually induction problems, also early/frequent waking or greatly increased sleep and complaints of increasing fatigue)
- Appetite/eating behaviour changes
- Feelings of boredom
- Emotional outbursts and highly impulsive behaviour
- History of withdrawal/isolation
- Hopeless/helpless feelings
- History of past suicide attempts, depression, psychological counselling
- History of suicide attempts in family or peers
- History of recurrent serious accidents
- Psychosomatic symptoms
- Suicidal ideation (including significant current and past losses)
- Decreased affect on interview, avoidance of eye contact--depression posturing
- Preoccupation with death (clothing, media, music, art).

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Appendix 6 MBS item numbers to GPs and Physicians for use in care of complex patients

Item 132/133 Physicians

Further information about useful MBS items at: www.health.gov.au/epc.



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