



### **Oxford Textbook of Palliative Care for Children (3 edn)**

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### **Adolescents and young adults**

**Chapter:** Adolescents and young adults

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### **Defining adolescence and young adulthood**



Defining a precise age range for adolescents and young adults (AYAs) is challenging, given the complex biologic and psychosocial developmental processes experienced by this group (1). Earlier puberty, continued growth well into the 20s, and delayed timing of role transitions in many countries (including completion of education, marriage, and parenthood) have shifted perceptions of when childhood ends, and adulthood begins (2). Although a 'life stage' approach may be most appropriate to help categorize the needs of this group, a range of 10-24 years of age is becoming widely supported.

### **The prevalence of LLC in AYAs**



Better supportive care for conditions that are manifested in childhood has contributed to increasing numbers of young people surviving into early adulthood, with the largest increase in prevalence of

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LLC over the last 10 years amongst 16–19-year olds (3). A UK study identified the prevalence of LLC per 10,000 population as 24 in the 11–15 age group, 23.1 in 16–20-year olds, and 21.1 in 21–25-year olds. Congenital anomalies were most prevalent in children aged 16–20 years when oncology diagnoses became most prevalent (3).

### Adolescence as a transition phase



Adolescence is the essential and inevitable period of development during which the adult identity is formed. Physical and biological development occurs alongside the emergence of emotional, physical, and cognitive independence, with a deeper discovery of self and the development of a personal value system. Even in the presence of deteriorating health and neurological and/or physical impairment, the transition to adulthood will continue with regard to many, if not all, of the tasks required.

One particular challenge in working with AYAs is their wide spectrum of developmental levels and cognitive abilities. Although there may be disease-related restrictions in achieving aspects of adult functioning, this group will also demonstrate a range of maturity, based on normal variation, life experience, and social opportunities. AYA services face the challenge of providing for and supporting those who are still childlike as well as those who are functionally mature adults.

### Normal adolescent development



An understanding of adolescent development is essential to the provision of palliative care for AYAs. The hormonal changes of early adolescence trigger rapid growth and mood swings. Capacity for abstract thought increases, with greater ability to understand consequences and plan for the future. Alongside these changes is a biological drive to socialize and identify with a peer group (4, 5).

Autonomy develops through risk-taking behaviour and testing of boundaries imposed by parents and authority figures. Sexual development triggers the emergence of physical desires and, for many young people, their first sexual experiences. These processes are essential to the development of adult identity and may at times be in conflict with previously accepted family beliefs and values as young people test out alternative options.

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By late adolescence, young adults are defining and understanding their roles in life with regard to their lifestyle, career, and relationships. They should have a sense of who they are, of those with whom they identify, and of the type of life they want to lead. This stage is characterized by making plans for the future, establishing permanent relationships, developing increased financial independence, and spending time away from the family.

### **Challenges to adolescent development in the palliative care population**



The restrictions and limitations imposed by illness, and by physical and cognitive delay or decline, will have a significant impact on a young person's ability and opportunity to transition through the developmental tasks of adolescence.

Chronic ill health may delay the onset of pubertal changes, including sexual development, so a young adult may appear and behave in a younger way than their peers. Many may not develop cognitive skills that accompany adolescence and those with neurodegenerative disorders may experience cognitive decline. Without maturity of abstract thought and the ability to understand consequences, they are less likely to achieve the same independence and levels of responsibility as their peers. Without such freedoms, opportunities to socialize with peers, to test boundaries, and to explore and experience sexuality are limited.

*I am aware that I can never be really independent because I have special needs and cannot get a job. But it's difficult. I don't want to sit at home and watch telly and I can't go on buses on my own (6, p. 27).*

With the potential or reality of an early death, making plans for the future may not seem worthwhile or possible. Unlike their peers, whose adult identity is often based on an assumption of immortality and endless opportunity, our patients must build an adult identity within the restrictions of physical and/or cognitive impairment and ill health.

### **Changing relationships with parents**



As AYAs seek an identity outside the family, relationships between the 'child' and parents change. Experiments with diverse personal choices, lifestyles, and values that are usually—and necessarily—different from those previously taught by parents are essential to establishing autonomy. Conflict between the young person and their parents is not unusual, especially when a previously compliant young person challenges parental control by refusing to comply with medical

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instructions or participates in social situations that their parents feel are unsafe.

AYAs feelings about their parents can be particularly complex and depend closely on their particular family and cultural background. Some are striving for or have previously experienced a degree of physical and emotional autonomy but declining health and/or physical or cognitive ability forces them towards dependence. The biological drive for independence competes with the need for physical and emotional support from the very people from whom they are trying to separate.

*At a time in adolescence when one is actually aware of one's body, it was very upsetting to have to be totally reliant on my parents and the nurses for even the most basic washing, toileting, and feeding—and without much privacy! (7, p. 272).*

### Peer group identification



Peer group identification is an essential determinant of adult identity; it is the way in which a young person starts to work out what sort of adult they want to be, by choosing a group that has an appearance and way of life to which they aspire. AYAs with physical and/or cognitive impairments may be unable to socialize independently with the peer group of their choice.

*Everyone around me is busy doing what I'm supposed to be doing but I can't.* AYA with cancer.

For others, the demands of treatments may restrict their freedom and ability to join in. An additional problem is that to be part of a group it is essential to be immersed in its culture, attitudes, values, and preoccupations. When facing continued or increasing physical and/or cognitive impairment, illness, and potential or inevitable death, the goals of their peers may seem futile and meaningless.

With deteriorating health and increasing social isolation, links with healthy peers are easily lost, and family and carers may almost inevitably become the young person's main source of social support and companionship. As the majority of carers are female, male companionship is frequently limited, further isolating young men in particular from peer identification.

### Independence



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## **Physical**

During early adolescence, young people go out with friends, stay at home alone, and sleep away from home. Many of our patients will not be independent even in their own homes unless specific adaptations have been made. If they need assistance with personal care, they may not have the flexibility to go out alone or with friends or come home late. Nighttime care needs usually make sleeping over at a friend's house impossible.

*But she wants to be 15 and talk about 15-year-old things. It's not the same doing things with your Mum (6, p. 29).*

## **Financial**

In early adulthood many young people find paid employment, giving them independent experience in the adult world, exposure to new peer groups, and their own income. Availability of work is often limited for our patient group, with physical limitations to accessibility, treatment regimens that have to be accommodated, and the need for absences due to ill health. Long-term financial prospects are similarly poor, as the developmental delay from their illness or interrupted schooling can hinder educational achievement. Access to higher education is difficult and many career paths are inaccessible.

## **Decision making**

When developing adult independence, young people start taking increasingly more responsibility for decisions about their own lives. Many of the choices healthy adolescents usually make are 'safe' in that they are unlikely to have long-term irreversible and detrimental consequences. Decisions that AYAs with LLC and life-threatening illness (LTI) face are often more complex and may be associated with significant consequences.

Truly informed choices are only possible if a person is aware of all the facts, can retain this information, and can understand and analyse the consequences of a decision. This requires complex cognitive processing, which some AYAs may never achieve, and others may lose if their neurological abilities deteriorate. Even where AYAs have this capacity, parents and professionals may not want to include them in every element of disclosure and clinical decision making, to protect them from the distress this knowledge may cause or from the burden of being involved in emotionally complex conversations. Some parents may be concerned that their child will make choices for the wrong reasons (e.g. refusing to continue treatment as a way of asserting autonomy). Other parents may be unable to recognize, or to accept, that their child has developed sufficient intellectual maturity to make these choices. Others still may

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feel such important decisions are only within the purview of adults to make.

Conflict can arise between and among families and professionals, or between these individuals and young people themselves, particularly if some feel that the young adult has a 'right to know everything' and others feel that the burden or responsibility involved is too great. Some family members or professionals may fail to recognize when the young person does not have a robust adult identity, values, or coping mechanisms. Others may 'safeguard' AYAs to prevent them from accessing the information and support they want and need to make sense of their lives and plan for their future.

There is a very real risk that decisions about care and treatments primarily involve the family and clinicians, with AYAs receiving only selected information. There is also a danger that they will be included in only some parts of the discussions, with limited information, and then be expected to make decisions in a world where nothing quite fits together.

There is an additional dilemma when disclosing information to a young person with neurodegenerative disease. Should we 'protect' them from information about what their future will become, or discuss this with them when they may not yet have the maturity and coping mechanisms to deal with the information?

### **Developing a sexual identity**



With progressive pubertal development comes the need for physical satisfaction and sexual relationships. Peer group isolation and limited independence means AYAs often miss out on peer information and discussion around sexuality and sexual practice, as well as opportunities for sexual relationships. Physical disabilities, or associated anxieties, can impair opportunities for sexual experiences, either with others or through masturbation. Personal expectations with regard to relationships and sexual experiences can become a major concern to AYAs, who may have no appropriate peer-group support and feel increasingly isolated. Those who are physically able may become overtly sexually active in an attempt to experience sexual relationships while they can and/or to achieve peer group acceptance and a sense of normality. Others may mourn the fact that they may not live to experience sexual intimacy.

Parents and carers may have difficulty recognizing or acknowledging a young person's sexual development and, where they do, are unsure how to support and facilitate their need for sexual experience.

### **Spiritual identity**



With the prospect of an early death, a person's spiritual and/or religious identity can assume increasing significance. Even if not expressed in these terms, many AYAs will look for meaning, purpose, and/or legacy. Many young people want to 'make their mark', aware that they

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have only a limited time. Some may embrace a spiritual or belief system more fully, whereas other may reject a previously held belief system. A need to retain hope, which can take different forms, is a common theme (8).

### Psychological development



The identity that develops during adolescence is fundamentally based on a sense of immortality, an expectation that one can determine and shape one's own future, and the belief that any errors made, or risks taken will have no significant consequences. Hope is an essential part of healthy development.

*Many of the young people, we realized, were already grieving for the loss of what their peers had got. Loss of their own lives; they were concerned about what would happen to their parents when they die (9, p. 347). Staff working at an AYA hospice.*

Many AYA with an LLC or LTI are aware that their own physical and/or cognitive decline and death are real and present. They cannot therefore develop their identity and autonomy from the same perspective as their peers, for whom 'anything is possible'. The very foundations of health, personal potential, and an open future on which adult identity is built are shattered. Feelings of anger and grief about their illness, anxiety about medical procedures, worries about family members, depression caused by separation from friends and normal activities, and fears of death are not uncommon (10). Physical differences from peers may cause feelings of being damaged and may impede peer group identification, further lowering self-esteem. At a time when acceptance and support are crucial, the young person may feel increasingly ostracized. At the same time, while they are biologically driven toward independence, they are trapped within or pushed back into increasing dependence and decreasing possibilities. Many will grieve for things they may not achieve, and some may take risks in their struggle for autonomy or in an attempt to gain acceptance.

### Supporting the transition to adulthood



One role of the professional is to facilitate emerging adult independence in the face of a disease that often forces the young person into the dependence of childhood. AYAs need support to continue the transition to adulthood, unimpeded as far as possible by physical, emotional, and spiritual distress. They face the complex tasks of developing and working towards goals for the future, while at the same time acknowledging and preparing for potential or inevitable death. This

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requires flexible, responsive, and tailored care that is rooted in open, effective communication and partnership.

### **Facilitating peer group interaction and independence**



Whatever their degree of physical and cognitive dependence, AYAs need opportunities to become as independent as possible. Home adaptations and equipment that enables them to control their own environment (e.g. electric wheelchair, self-operated hoist) create opportunities for independence and privacy both in and away from home. Where opportunities exist for equipment and housing modifications, forward planning can help prevent delays due to transfer to adult services. In these cases, good communication and clear budget allocation between agencies are essential in order to avoid families being hampered by bureaucracy or forced to rely on crisis intervention. Where such resources are not available, families and communities may be able to collaborate to find other creative ways to support young people's independence.

Creating opportunities for socializing independently, with peers of all abilities, helps combat isolation. The Internet, which has ever-increasing penetration across most regions of the globe, facilitates connections with others and allows for exploration of social networks. Many disease-specific support groups have websites and chat rooms, so AYAs have the opportunity to communicate with other young people with similar needs to their own. Face-to-face meetings and facilitated groups support in-person interactions.

*I realize that everyone there had something in common with me, and that I could talk to them, and I could just mess around and be a kid again; and so ... it definitely helped me break out of my shell again (11, p. 75). Participant from a group AYA activity.*

School attendance should be encouraged, as much for social interaction as for educational purposes, and schools will value support as they embrace the changing needs of AYAs, particularly those with deteriorating health and abilities. If a young person is unable to attend school, alternative social (not just educational) provision should be made.

Where possible, opportunities for continued education, including university, career support, and financial independence should be facilitated. Professionals with familiarity in these areas can help AYAs become aware of their future care needs and benefit entitlements, so that they can plan their future living arrangements.

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With adequate information and support, even those young people with severe physical and cognitive impairment or decline may be able to take over the organization of at least part of their own life. Others may become fully independent or may be able to live away from home if access to support from an independent carer is available.

### Support for sexual development



Sex education is important for all young people, but especially those who may have limited access to education through school and peers. For several disorders, more specific information about sexual activity and fertility is essential. For example, it is not unusual for young adults with cancer to assume that they are infertile. Sexuality and sexual function, with practical advice and support, should be routinely discussed openly with all AYA patients (12).

*I think they [some staff] do struggle with sexuality, when the lads are talking about the sexuality and stuff, yeah, I think they do get embarrassed a little bit; don't know how to deal with this. And I think you've got to have staff that are prepared to tackle those sorts of things with the youngsters, working with them (9, p. 349). Staff working at an AYA hospice.*

Providing opportunities for peer group interaction away from parents, which include structured sexual education and emotional support, may be one way to address some of these issues (13).

### Spiritual support



The need to find meaning and purpose in life can become increasingly acute in the anticipation of an early death. Young adulthood is also the time of questioning previously held beliefs and family values, so the need to find meaning and purpose coincides with the natural developmental step of questioning what was previously accepted. Professionals working with AYA should offer spiritual support in whatever way is appropriate for each young person. This may, for example, be enabling the expression of beliefs, fears, and doubts, or may be providing support with exploration of religious beliefs. There should be access to multi-faith support, but the provision of spiritual support should not be seen exclusively as the role of a chaplain or faith group leader or solely rooted in a formal religious belief system.

### Support for decision-making



The extent to which AYAs can be involved in decisions about their own life and healthcare will vary. Some will have, or will achieve, the emotional and intellectual maturity to understand actual and hypothetical concepts and the consequences of possible actions. Others

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may not achieve, or may lose, this ability. Many will need assistance in understanding the available options, future risks, and consequences of their choices.

Furthermore, the influence of cultural background may feature prominently in these situations. Objectives of adolescent independence and individual autonomy can run counter to notions of familial decision making and respect for elders. Legal structures, for example concerning consent, are likely to vary between countries and regions as well. Given that the governing bodies and the values of people living in different cultures can differ markedly, the decision-making process must be flexible and adaptable, to prevent erosion of the relationship between young people and their families.

*I think, you know, there's a big protection racket goes on between young people and the parents. So, parents don't want to discuss something because ... they don't want to upset their teenager, young adult. But equally, or I think more prevalent, the opposite is true, that the young people are not as open sometimes with their parents because they know that will upset them. You know, they know about their conditions, they know their futures. They know what's possible and probably what's not likely ... [one young person said] "I want you to be there [staff member] because I can't be as honest in front of my mum because ... I don't want to upset her and I want to tell, I want to say what I want to say" (9, p. 347). Staff working at an AYA hospice.*

Open, honest communication with AYAs is essential from the time of the first meeting but must be guided by the young person. Parents should be encouraged to include their child in safe discussions and decisions from an early age, in preparation for their increasing responsibility as they approach and enter adulthood. Regardless of age, young adults should be given appropriate opportunities to be fully informed about their disease and prognosis and supported through decisions about their own treatments and how to spend the time they have left. The timing and pace at which this information is given must be carefully judged and led by the young person.

It can be helpful to discuss with the family and the young person, at an early stage, whether they would like to receive information as a family group or individually, and to ask the young person how much information they want to be given, who should give it, and who they would like to be present, even if it is difficult and distressing information. Those with cognitive impairment should also be encouraged and enabled to take part

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in at least some aspects of decision-making, and it is suggested that they have independent advocates to support them (14).

It is important to remember that many AYAs may have little experience of independence and involvement in decision-making. They may still have an expectation of and a security in parents taking a dominant role in discussions and decisions. Some, although capable of independent decision-making, and despite appropriate support, will not want to be fully informed of their diagnosis and prognosis, and will devolve responsibility for medical discussions and decision-making to their parents, as a way of coping. Where parents have tended historically to make most decisions for the young person, an AYA may simply default to that position and/or this may be what parents prefer.

Professionals should also be aware that some young adults may exercise their right to make decisions as a way of pushing personal boundaries, or of punishing or upsetting their parents or carers. In this situation and in general, explanation and negotiation between parents, health professionals, and the young person, and recognition of influences such as culture and background, are essential.

### Psychological support



Young adults need time and space to express their fears and concerns, to have these acknowledged, and to be supported. Opportunities to socialize with other young adults in a similar situation will facilitate peer support, but opportunities for individual and group support by experienced professionals can be helpful where available (16).

Many young people who are facing death will continue to have ordinary plans and wishes for the future, even with the knowledge these will not be realized. A skilled professional will be able to acknowledge and respect these dreams, while maintaining honest communication. It is important and normal to balance unachievable goals with goals that can be realized.

*I'd always thought that I was going to live a long time. I'd done things very slowly without a sense of urgency. It was just all these things that I haven't been able to do yet that I would like to do—travel, go live in another country, so much to read and see and do. All this is quite severely limited and probably is just off the table (15, p. 403). AYA with metastatic cancer.*

Relationships with siblings and parents should be considered during provision of psychological support. Both the young person and their parents may need support to acknowledge that, despite the drive for adult independence and separation from their parents, there is an ongoing need for emotional and physical support. Sibling relationships

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can be strong, but the burden on a healthy sibling can be tremendous (16). They may be the main confidant of the life-limited sibling, while worrying about their parents' coping abilities and the conflicting need to pursue their own life. They may experience displacement, deprivation, anger, injustice, loneliness, and vulnerability, as their parents have insufficient time for them. Without the right support, these feelings can cause resentment and disruption of their relationships within the family.

*I do think there is a place for, like, for instance, say this last month when Y has been really poorly, that, you know, just to have somebody there or a system for older siblings, that they can access .... I don't mean a group, but just that they may have a contact person .... if they need to make a phone call or are kind of bogged down or just need a chat, that they have somebody to have contact with (9, p. 348). Parent of an AYA in a hospice.*

Where skilled psychological support for the whole family, individually and together, is not available, professionals can still help to prepare the family for what they may experience by noting potential difficulties in family dynamics ahead of time and proactively identifying possible solutions.

### Respite care



Appropriate respite facilities for AYAs are scarce. Paediatric hospices are often inappropriate for a mature young adult who is, or has been, relatively independent. Adult hospices can be equally inappropriate, as the majority of users are middle-aged or elderly and unwell, rather than active young people.

As a group, AYAs have specific needs when receiving respite care. They often want to stay up late at night and spend the day in bed, listen to their own music, watch films and television programmes for adults, and be noisy without fear of disturbing younger children or older adults. They want personal space and privacy, but also to be with people of their own age. Most of all, they want to be somewhere where they 'fit in'.

Wherever respite is provided, staff should identify whether they are able to support the specific needs of AYAs, particularly in relation to social activities, the need for support to explore their sexual and spiritual development, and the promotion of autonomy. At the least, staff may liaise with AYAs, families, and their usual providers to tailor care.

### Advance care planning



AYAs should be involved in the decision-making process as much as possible and in a culturally and developmentally appropriate manner at the end of life. Discussions with seriously ill young people are

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often withheld, due to concern that these conversations would be too stressful or might send the message that the medical team wishes to withdraw care. Healthcare professionals may feel uncomfortable, unprepared, or unskilled at conducting these conversations, or may feel they do not have the time. Parents may feel anxious about their child being involved in such emotionally difficult discussions and decisions.

Evidence suggests many AYAs appreciate involvement in open and honest discussions, including about advance care planning, and if talk is avoided, parents may feel resentful or fearful later. Supporting AYA involvement in end-of-life planning can help parents and healthcare providers make informed decisions, alleviate distress, avoid decisional regret, and perhaps improve the patient's quality of life by respecting their values, beliefs, and preferences (17).

*The avoidance or lack of conversation about impending death by adults around them creates a sense of isolation, fear, and anxiety .... Ultimately, it places youth at risk for dying in emotional isolation (18, p. 902).*

As a means to start the conversation, advance care planning documents such as Voicing My CHOICES™ are geared specifically toward young people, to provide patients with the opportunity to express their preferences for how they want to be treated if they cannot speak for themselves. Some examples of how to introduce the concept of advance care planning to patients and families include (19):

1. *'While we are hopeful that your treatment will be effective against your disease, we have learned from other families like your own that not suggesting that you give some thought to some difficult issues early on is irresponsible of us. For example, it would be great if you would communicate with each other about who would be the person to make medical decisions for you if you became very ill and not able to do so on your own' (17, p. 718).*
2. *'Although we are hoping that this next treatment [medicine] will be helpful, many people your age have told us that they found it helpful to have a say about what they would want or not want if treatment doesn't go as expected. In fact, people your age helped create a guide so that they could put down on paper the things that are important to them' (19, p. 594).*

AYAs want to discuss end-of-life issues with the healthcare providers they trust and who have been honest with them from the inception of care. Healthcare providers must delicately balance the need to respect and maintain hope while promoting meaningful conversations throughout the illness trajectory, including when death approaches. These conversations can be complicated with adolescents who are dealing with cognitive,

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emotional, physical, and social transitions across a wide spectrum of family and cultural backgrounds. By opening difficult conversations compassionately and being able to document thoughts about end of life and remembrance concerns, young people have the opportunity to give meaning to their life and their family's emotional needs after their death.

### Transition to adult services



Transition is meant to be a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of AYAs with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems (20).

Differences between paediatric and adult services can be vast. Paediatric services are generally family-centered and multidisciplinary, with access to therapies and recognized routes to respite care. Adult services tend to be tailored to meet the needs of independent adults, handing the patient responsibility for their own care and coordination. Additionally, in palliative care the adult sector has been traditionally more focused on end-of-life care, rather than care throughout the whole illness trajectory.

The care of AYAs is challenging, as they are a small unique group within both adult and paediatric services, fitting easily into neither. They have often outgrown paediatric services, yet it can be difficult for professionals, particularly those who have known the young person and family for many years, to 'let go' (21) and for families to feel confident in a new and unfamiliar adult setting. This can be especially hard when AYAs have conditions rarely seen in adult practice. AYAs also have little, if any, experience of independent adulthood and decision-making, so may struggle in an environment where this is expected.

Some paediatric services extend their coverage beyond the age of 18 years, particularly if a young person is approaching death, and some will keep young adults in paediatric services as they feel they are more emotionally or cognitively suited to this environment. However, such practice denies these young people their emerging adulthood and undermines their value and role in adult society. It also impedes access to some areas of support that are given less attention in paediatric services, such as help with employment and independent living (21, 22).

Little evidence exists to support a specific transition model for palliative care. Some disease-specific models work well, for example for cystic fibrosis or congenital heart disease, because there is a clearly identified adult service on the receiving end (21). However, many young people have disorders which do not fit easily into a disease or system-specific category, such as the rare, orphan conditions, and it is also a problem for those young people who are accessing multiple specialists at any one time.

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There is growing recognition of the need to adapt adult services to better collaborate with the paediatric sector, to better understand the health conditions encountered, and to feel more confident talking with young people about their concerns (23). Paediatric services also need a better understanding of what adult services can offer and the opportunities they provide. Partnerships between adult and paediatric palliative care teams are likely to offer a solution (25) with joint consultation throughout a transition phase.

A community-based transition approach that starts early and includes components such as social, educational, and career needs (20) is feasible and effective. Starting to prepare for transition at 13–14 years allows time to identify and address specific concerns, as well as preparing the young person and their parents for their changing roles. Readiness assessment tools and health plans for transition are available to support and document the process.

Paediatric and adult services should actively work together, where possible, to ensure joint care planning and care provision, to enable a smooth transition (23). Joint clinics with paediatric and adult staff from multiple disciplines can enable the young person and their family to build up confidence in the new team before transferring care completely. This approach increases patient satisfaction and promotes the professional links necessary for good transition. Some teams designate a specific professional or have a liaison nurse who acts as a link. If available, psychological support provided before and during the transfer should be continued while the young person settles into the new environment.

For those young adults who do not clearly ‘fit’ into an existing or new adult service, the family doctor may be the most appropriate professional to oversee and coordinate their continuing care (22). The family doctor should be supported by paediatric services during the transition, and by the adult specialist and the adult palliative care teams following transfer. Many young people will continue to need the additional support of specialist tertiary centres, but the family doctor can maintain the essential overview and coordination of professional support and care. The family doctor may also have access to other essential community-based services (e.g. district nursing, community physiotherapy, occupational therapy) which were previously accessed through community paediatric services.

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During the transition process, AYAs want knowledgeable providers, coordinated and accessible services, to be respected and valued, and to have their independence promoted and supported. Where multidisciplinary and multiagency system solutions exist, their focus on patient priorities is likely to be the best way to provide seamless resources to support young people's health, educational, vocational, and social goals, in their quest to maximize opportunities for young adult experiences during their limited lives (26).

### **The needs of professional staff and carers**



Staff who work with young adults should have an interest in and a commitment to working with this age group, as well as the ability to communicate and empathize with them. More specifically, the Report of the Joint Working Party on Palliative Care for Adolescents and Young Adults (6) recommends a basic understanding of the developmental stages of normal adolescence, ethical issues in working with young people, the effects of grief and loss, the impact on families, partners, and close friends, cultural diversity, and spiritual needs.

For those looking to acquire new or additional experience working with this population, where possible, the following settings may provide opportunities to develop and hone skills:

- Experience in the community to gain experience of care in different locations, an insight into family problems, and the diversity of professionals involved.
- Experience in a specialist unit providing care for diseases such as muscular dystrophy, cystic fibrosis, or cancer, where care is coordinated from the hospital.
- Attachment to a children's hospice or an associated primary care team to gain experience of a wide cross-section of life-limiting conditions (LLC) and to have the opportunity to spend time with the parents.
- Attachment to psychology or to a palliative care team to acquire counselling and communication skills.
- A training placement to gain knowledge of physical symptom control, perhaps with a paediatric or adult palliative care team. (6)

*Young people affect you mightily more than somebody who has lived a full life ... it was just the unjustness of why somebody could be plucked away (24, p. 542). Adult palliative care nurse working with AYA.*

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Individual and team support for those working with young adults is essential. The powerful feelings that young people often need to explore, as they grieve future losses and try to make sense of their life in the context of illness and premature death, can be emotionally draining for staff, who will need regular support and supervision. Self-awareness and maintenance of professional boundaries are essential in order to avoid responding to young people as social friends or as though the young person was their own child.

### Service development



One promising model of service development involves the assignment of a named key worker with specialist knowledge and training to support each AYA's specific needs. The key worker should be familiar with local clinical and social support services and how to access them and should support the young person to be as independent as possible. Services may then be passed on from the key worker to the professional who will maintain this role in the future.

Development of central specialist clinics for young adults with rare conditions may be important, and with the aid of such centres, physicians in adult services could develop expertise in the care of these young people. Primary care teams should have opportunities for training in palliative care, and also for training to support transition and in continued care and coordination of care through adult life.

Appropriate respite care needs to be more readily available, with clear and easy routes of access. Social opportunities should be provided both within a respite setting and in the community. Each young person must be assessed and provided with appropriate aids for independence, where possible. A proper system of purchasing, maintaining, upgrading, and replacing aids and equipment must be in place and should be monitored.

Well-coordinated multidisciplinary and multiagency support for the young person to achieve educational goals is a crucial target. This should include careers advice and assistance with attending higher education or accessing employment.

Above all, flexibility and choice in service provision are important, with the young person making decisions whenever possible.

### Summary



The transition from child to autonomous adult is characterized by hormonal, physical, emotional, and cognitive changes that occur over a number of years. Having a potentially fatal condition will have a huge impact on the developing adult identity, due to the challenges this presents at such a crucial and complex developmental stage.

## Adolescents and young adults

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Cognitive and emotional changes drive the young adult to pursue individuality and independence, but their opportunities to experience and achieve these are limited. Ill health and physical or cognitive deterioration can push them back into the dependence of childhood. The sense of immortality and freedom that is crucial to shaping a young person's future is often replaced by increasing dependence and the reality of what will never be achieved. The psychological perspectives on which adulthood is established are very different to those of their healthy peers. Supporting the young person through this transition towards adulthood, unimpeded as far as possible by the barriers imposed by an LLC or LTI, requires well-planned, flexible, and responsive support from experienced professionals.

Staff who are working with AYAs must be aware of the difficulties that are faced in adolescence and the impact that an LLC or LTI has on these, not only for the young person, but also for their family and carers. They should be able to support the young person through the transition to adulthood and help them to achieve as much autonomy as possible. They must also be aware that many families and carers need support to allow the young person to make the transition to adulthood, recognizing what can be achieved as well as what cannot.

Transfer to adult services should be well coordinated and planned in advance, identifying appropriate services to smoothly take on the continuing care. At the same time, young people should be given the opportunity to take an increasing role in responsibility for, and decision-making about, their own healthcare, as well as other aspects of their own life.

Palliative care services must support and facilitate the young person in this transition to adulthood, while at the same time preparing them for potential or inevitable death and providing them with support in relation to this. With the right support, a young person's sense of individuality, autonomy, value, and continuity can be developed and reinforced, and they will be able to embrace and plan for a future in whatever form that takes.

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