

Engaging young people with a chronic illness



Emily V Wilson



Background

General practitioners (GPs) are uniquely placed to help adolescents take control of managing their chronic illness, and provide continuity of care during the transition to adulthood. This is dependent on a well-established therapeutic relationship with a young person and their family.

Objectives

The aim of this article is to address the preferences of young people with a chronic illness in dealing with doctors. It also covers ways in which GPs might frame chronic illness management to young patients and their families to optimise care.

Discussion

Young people want their doctors to be honest, trustworthy and friendly. Plain language explanations of confidentiality, the patient's illness, management and transition are likely to foster a good therapeutic relationship. Attention should be paid to the difficult balance between managing an illness and enjoying life.

Chronic illness and adolescence

Navigating adolescence is difficult, especially with the added complexity of a chronic illness. Parents may have been the primary managers and decision-makers for an adolescent's chronic illness for many years. They may be understandably nervous about a young person taking control, or be critical of perceived bad decision-making, particularly with regards to adherence to a treatment plan. General practitioners (GPs) are in the middle of this power shift around illness management. They can advise and manage parental stress, while at the same time, support a young person to develop greater autonomy.

Adolescence is a time when most young people are still dependent on their parents and are more likely to conceal activities from them for fear of losing privileges.^{1,2} Developmentally, adolescents are gaining an awareness of the personal attitudes and behaviours of others. In early adolescence, they may be acutely sensitive to being judged, but towards adulthood will mature and have a broader understanding of others' perceptions.¹

Developing rapport

Trust and good communication

Trust is an important aspect of any doctor–patient relationship and critical when caring for adolescents.³ Adolescents are likely to withhold information they think will be viewed negatively, either by not asking questions (eg about unprotected sex) or giving inaccurate responses.⁴ They may do this for fear of judgment, criticism or hospitalisation (from revealing a symptom deterioration).⁴ Yet, honesty and trustworthiness are two of the qualities identified by adolescents as making a good doctor–patient relationship^{1,3,4} (Table 1:1a).

Honesty is mentioned specifically by young people with a chronic illness as being a desirable quality in a doctor.^{1,3} Adolescents are more likely to raise questions about their illness with a health professional they have known the longest,⁴ as the

Table 1. In their own words – Quotations from qualitative research around young people’s views on good and bad doctors

Theme	Quotation from a young person
1. Trust and good communication	<p>a) 'If there's something wrong with you, you trust 'em to tell you.' – Female, aged 15 years, without a chronic illness¹</p> <p>b) 'It would be better to just have one doctor so we could move onto different parts of epilepsy instead of getting the same questions again and again.' – Female, aged 15 years, with epilepsy⁴</p> <p>c) 'You don't tell the doctor anything because you don't want them [student doctors] to hear.' – Female, aged 14 years, with arthritis⁴</p> <p>d) '[My doctor is] the sort of person you could tell anything to, not the sort to tell you off for it.' – Male, aged 15 years, with diabetes⁴</p>
2. Confidentiality	<p>a) 'He needs to keep that [conversation during doctor visit] zipped, especially when they talk to your parents afterwards.' – Female, aged 16 years, with cystic fibrosis¹</p> <p>b) 'If I told my doctor something really personal that nobody else needed to know, and then he went and told everybody, I don't care if it's people on the hospital staff, sometimes I'll be like "Uhhh, could you just keep this between us" and if they go and tell everybody, that would make you lose trust in the doctor.' – Male, aged 19 years, with sickle cell¹</p> <p>c) 'A doctor a long time ago when I was about six, he sent my records all the way down to Children's [Hospital] and it was not like what a normal doctor would do.' – Male, aged 13 years, without a chronic illness¹</p>
3. Involving parents	<p>a) 'I go to see him, but not sure why 'cos mum talks about things.' – Female, aged 10 years, with epilepsy⁴</p> <p>b) 'Some doctors still think that dad or mum is more important than me, and they have to talk to them instead of me. But it's not good talking to them. I'm the one with the cough.' – Female, aged 11 years, with cystic fibrosis⁴</p> <p>c) 'Speaking to a doctor is nerve wracking.' – Female, aged 11 years, with diabetes⁴</p> <p>d) 'I would ask but I'm shy [when speaking to my doctor] – not got the guts to.' – Male, aged 11 years, with epilepsy⁴</p>
4. A high standard of patient-centred care	<p>a) 'He's more interested in what's happening inside me than what I'm going to ask.' – Female, aged 11 years, with diabetes⁴</p> <p>b) '[A good doctor] would be a friend with the patient, not just be an authority [figure].' – Female, aged 16 years, without a chronic illness¹</p> <p>c) 'Have a conversation with them, not like question-answer, question-answer, having a conversation so it all flows.' – Male, aged 14 years, with Crohn's disease¹</p> <p>d) "'How are you?" is not a good question!' – Female, aged 11 years, with diabetes⁴</p> <p>e) 'You see her more as a doctor dealing with your treatment rather than other aspects of your arthritis.' – Female, aged 14 years, with arthritis⁴</p>
5. Holding back	<p>a) 'It's easy to ask questions about things that don't bother me.' – Male, aged 14 years, with cystic fibrosis⁴</p> <p>b) 'If when I'm older, I've still got CF [cystic fibrosis] and I do less stuff [physiotherapy], will my lungs and openings start closing? This is quite a big worry, but I don't want to talk to anyone about it.' – Female, aged 12 years, with cystic fibrosis⁴</p> <p>c) 'Sometimes I think the question would be hard for the doctors, and the answer might not be a nice answer. I might not want to know it. One day I might get so weak I can't move. I might like to know but it might make me sad, so I don't want to know. I'll just wait until it happens and I'll manage it.' – Male, aged 10 years, with muscular dystrophy⁴</p> <p>d) 'There's hardly any time where [my doctor] keeps something from me. I think the only way he'd keep something from me is if I wasn't ready to hear it or if it really didn't concern what I did just as long as my parents know about it.' – Female, aged 16 years, with cystic fibrosis¹</p>

duration of a relationship with a doctor has been identified as a predictor of trust.¹ Communication is best facilitated by having the same doctor for each visit⁴ (Table 1:1b), without extraneous people (eg medical students;⁴ Table 1:1c), in a setting that de-emphasises the doctor–patient hierarchy⁴ (Table 1:1d).

Confidentiality

Young people want to be offered an opportunity to speak privately with their doctor.³ Adolescents have varied views on the definition of confidentiality and the kind of information they want kept confidential. Some of the ways adolescents see confidentiality are

straightforward (Table 1:2a); however, some of their definitions are different from the standard definitions clinicians adopt in healthcare. In particular, adolescents may view information-sharing between healthcare professionals as a breach of the trust they have in their doctor¹ (Table 1:2b–2c).

Given that ambiguity could harm a therapeutic relationship, it is worth clarifying confidentiality both at the start and end of a consultation. Clarifying at the start may involve explaining the role of clinical note-taking and who will have access to those notes, as well as the legal limits of confidentiality around harm to self and others. Clarifying at the end may involve explaining who

will receive a referral letter, what information it will contain, and the purpose of communicating the information. Ask specifically about information discussed in a private consultation that the adolescent would like omitted from discussions with parents. Briefly outline aspects of care you think should be discussed with parents and any reasons for this. If there is any conflict, consider Gillick competence.

Involving parents

Parents often dominate medical appointments in a dynamic that marginalises the young person.⁴ Doctors sometimes contribute to this by focusing on parents and directing questions to them⁴ (Table 1:3a–3b). This is often driven by a parent's need to consult with a doctor about their own concerns in relation to their child's illness.⁴ This dynamic needs to be carefully managed, particularly where a GP may have a therapeutic relationship with a parent that is separate from the presentation with a child.

While many young people prefer their doctor to address them directly,³ some find doctors intimidating⁴ (Table 1:3c–3d). Some young people even report that it is helpful to rehearse questions with their parents prior to an appointment.⁴ The perceived power imbalance is greater with younger age, and between teenage girls and male doctors (teenage boys express no gender preference for their doctor).^{3,4}

Young people with a serious or life-threatening chronic illness are more likely to want their parents to be involved in decision-making around care.^{1,5} They are also more likely to consider their parents as acceptable recipients of bad news on their behalf,^{1,5} and expect a doctor to deliver this news to their parents.⁵

A high standard of patient-centred care

Young people with a chronic illness self-identify a need for accurate information, and have a higher expectation that doctors will act on their behalf.¹ Adolescents want doctors to have a high level of competence in managing their condition.^{1,3} Use of unusual words or medical terminology can inhibit communication.⁴ Young people want their condition and management explained to them in a language they can understand, with particular attention to pain and comfort.^{3,6} There is also a preference for person-centred care, rather than condition-centred care⁴ (Table 1:4a).

Young people want talking to their doctor to feel like talking to a friend¹ (Table 1:4b), a desire that is underestimated by doctors.⁶ Small talk is a suggested means of introducing sensitive topics¹ (Table 1:4c); however, young people may find it hard to answer general or non-specific questions⁴ (Table 1:4d). Specific questions to ask might include: 'Can you tell me what you did on the weekend?' or 'Are there things you miss out on doing because of your diabetes?'

Information about coping with a chronic condition in day-to-day life is as important as information on the condition and its treatment for young people.⁴ Unfortunately, adolescents do not report healthcare professionals as a primary resource in seeking

this information.⁴ Young people can have a sense that doctors are not interested in, or aware of, the wider implications of their illness⁴ (Table 1:4e).

Holding back

Even with a good doctor–patient relationship, young people admit that there are some aspects of their chronic illness they cannot discuss⁴ (Table 1:5a). This can be especially true for those with life-limiting illnesses where answers to questions on prognosis are difficult to hear⁴ (Table 1:5b–5c).

In some cases, it may be appropriate for parents to receive information first and act as gatekeepers (eg when communicating a diagnosis of cancer or relapse).⁵ When asked if there are times when a doctor should not share bad news, adolescents responded that it should be shared with their parents first¹ (Table 1:5d).

Adolescents may make a conscious choice to avoid information that may cause distress. Counteracting this may result in a loss of hope or lowering of morale.⁴ Caution should be taken where this can be anticipated, as giving information that the adolescent has chosen not to ask about may be detrimental to the therapeutic relationship.

Managing missing out – School and socialising

Teachers and other caregivers can be anxious about young people with chronic illnesses. GPs are in a position to support meeting a young person's care needs, while ensuring they are not unnecessarily excluded from fun activities. Some rare or complex conditions may have unique day-to-day care needs, which may warrant specific clarification through consultation with the treating specialist.

Many schools have established pathways for managing chronic illness. These can involve a specific document proforma or care plan from an established body, such as the National Asthma Foundation Australia. Finding out the preferred format of a care plan can prevent going back-and-forth between the school and doctor. Involving adolescents in decision-making around activities they feel they can do, and ways they could be accommodated, is a helpful way of framing a young person's care as inclusive, rather than exclusionary. Proactive communication can also prevent conflict between families, school and medical staff regarding exclusion.

Event-specific care plans may be helpful for activities where more is asked of an organisation (eg school camps). A specific care plan might include:

- medication administration (name and times)
- emergency management plan (medication name and indication)
- names of staff members trained to administer emergency medication
- medical professionals who may be contacted if parents are unavailable.

Schools are generally quick to call an ambulance for emergency care. For young people accustomed to managing their chronic illness, it can be disempowering for a perceived emergency to override their wish to remain at an activity. Clarification of situations where a young person can remain at an activity can be helpful (eg after recovery from a typical seizure in a patient with a known seizure disorder). Where relevant, specialists may have valuable input into which clinical situations do not require presentation to hospital. When getting to know a family, asking for contact details of a school support person and permission to release medical information to them can facilitate development of a care plan that is comfortable for all.

Sex, smoking, drugs and alcohol

Chronic illness in adolescence does not preclude high-risk behaviours.⁷ Sexual activities, smoking, drugs and alcohol may all be used for peer acceptance, enjoyment and stress relief. The risks and benefits of these behaviours are likely to be weighed by the adolescent in a holistic way, which also takes into account social consequences, rather than purely a biological way, considering only the effect of a behaviour on their illness. Learning about risk-taking and consequences is a healthy part of any adolescent's journey to adulthood.⁸

Chronically ill young people are just as likely as their peers to be sexually active.^{7,9} They may use contraception, but have often not been advised about it by a health professional, and have higher rates of sexually transmissible diseases and pregnancy.⁷ This is concerning given their increased frequency of physician contact,^{7,10} as well as the potential for cumulative risk to their health.

Rates of substance use in young people with a chronic illness are lower than their age-matched peers, with smoking and alcohol being most common.⁷ Cannabis or alcohol may be used to manage symptoms.⁷ In general, direct questioning about risky behaviours is preferred.⁶

Doctors are not good at detecting adolescent substance-use disorders on the basis of clinical impression alone. A specifically designed clinical instrument is more reliable at identifying a problem.^{11,12} For example, the 'CRAFFT' screening interview is a simple and very practical health-screening tool designed for use with adolescents to screen for high-risk alcohol-use and other drug-use disorders (available at www.childrenshospital.org/ceasar/crafft/screening-interview).

Where appropriate, planning for drug/medication interactions is likely to be helpful for those using substances. An awareness of other situational factors around substance use (eg long periods of fasting while drinking, staying up late or sleeping in and missing morning medication times) should factor into these plans.

Adherence

Adherence is the extent to which a person's behaviour corresponds with agreed recommendations from a healthcare provider.^{13,14} Treatment adherence can be a problem in

adolescence.^{2,15} Most barriers to adherence reported by adolescents are not disease-specific and include:²

- forgetfulness
- wishing to strive for normalcy (perceiving medication-taking as abnormal)
- consideration of stigma or opinions of peers
- conflict with parents.

The evidence base for interventions to improve adherence in adolescents is plagued by studies of poor quality.¹³ Studies have not targeted those who have poor adherence,^{13,16} have excluded patients with mental illness or a comorbidity,¹³ and have been unblinded.¹³ Of interventions used to promote adherence, educational strategies are inferior to trialled behavioural modifications, and psychological interventions have failed to demonstrate a beneficial effect on medication adherence.¹⁶

Some developmental stages of adolescence require compromise in a care plan to allow for more independence and responsibility.¹⁷ This often involves a risk-mitigation approach to care. An example might be accepting poorer glycaemic control on a twice-daily insulin regimen rather than insisting on tighter control that results in total non-adherence. The optimal level of parental engagement with promoting adherence is not yet clear; however, from a developmental standpoint, family-based interventions may be more effective for younger adolescents, and adult role models may benefit older adolescents.¹³

Transition to adult care

Difficulty with transitioning to adult care correlates with the difficulty of living with a chronic illness.¹⁸ Those finding it difficult to live with their chronic illness are likely to feel attached to their paediatric doctors, and want more information about future supports.¹⁸ During transition, some adolescents want more independence in managing their condition, while others want the family to remain involved.¹⁸

Box 1. Elements for successful transition

Consensus on essential elements for successful transition from a Delphi study of 37 experts in adolescent/young adult medicine:²³

- Assuring good coordination (eg timing of transfer, communication, follow-up, remaining available as a consultant) between paediatric and adult professionals
- Starting planning transition at an early age (and at least one year before the transfer boundary)
- Discussing with patient and family about self-management
- Including young person's views and preferences to the planning of transition
- If developmentally appropriate, seeing the adolescent alone at least for part of the consultation
- Identifying an adult provider willing to take on the young patient before transfer
- Tailoring the transition plan to the needs of the patient and family

Many studies have demonstrated that good transition processes are beneficial for young people with a chronic illness;^{19–22} however, a lack of high-quality evidence as to the optimal transition process means guidelines are consensus-based²³ (Box 1).

Practically speaking, having a written referral letter has been found to be protective against having a gap in care.²⁴ Ideally, transfer of care should occur directly between paediatric and adult specialists. The involvement of multiple specialists can complicate the coordination of transition. Many paediatric specialty services are becoming more aware of the need for proactive care planning around transition, and some have dedicated services and resources to assist with this.²⁵ Planning early is advisable, given that the traditional age for healthcare transition is a time when other aspects of an adolescent's life may be undergoing change (eg moving location for higher education or work).

Conclusion

The challenge when looking after young people with a chronic illness is how to best serve their health and developmental needs, while also supporting their parents. Adolescents want professional, caring, honest and supportive healthcare providers who take a holistic approach to care. They require support to enjoy life while dealing with the difficulties associated with managing a chronic illness and the transition to adult healthcare.

Key points

- Assist young people with gaining control over their illness while supporting their parents.
- Address young people directly and offer time without parents during a consultation.
- Take time to explain illness, management and medical terms.
- Focus on practical ways to enhance quality of life.
- Normalise reduced adherence and risk-taking behaviours.
- Plan early for transition to adult services.

Author

Emily V Wilson MBBS, Advanced Trainee in General Paediatrics, Adolescent and Young Adult Medicine, Royal Australasian College of Physicians; Paediatric Registrar, Royal Darwin Hospital, Darwin, NT; Research Associate, Murdoch Childrens Research Institute, Melbourne, Vic. emily.wilson@mcri.edu.au

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correspondence afp@racgp.org.au