

### Adolescence: boundaries and connections

An RCN guide for working with young people



### Acknowledgements

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**Marcelle de Sousa** Chair RCN Adolescent Health Forum

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All scenarios contained within this document have been developed by nurses who were involved in the writing of the text. The scenarios are therefore an amalgamation of experiences and were developed to illustrate the principles of care. The names bear no relation to any persons and any similarities between situations and names are coincidental.

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### Foreword

I am delighted to have been asked to write the foreword to this text, particularly as the need originated from our members and young people themselves. The work of the RCN Adolescent Health Forum in promoting the specific needs of young people is widely known, not just within our college, but by other professional organisations and health departments across Scotland, Wales, Northern Ireland and England.

Until fairly recently adolescent health did not particularly feature within our health policy, nor in practice or service planning. Nurses working with, or caring for, young people often had not received any specific training and felt unsupported when working with them.

The discussion groups highlighted that while there are examples of exemplary practice, service development, education and training for nurses and others in relation to the specific needs of young people, this is not universal. Greater standardisation and emphasis must be encompassed within pre-registration nursing education curricula.

This guidance will help signpost nurses to further resources and advice. The guide provides basic advice related to practice based scenarios, thereby enabling practitioners to apply knowledge and to work with young people confidently.

### Dr Peter Carter

Chief Executive & General Secretary

### 1. Introduction

"If you're trained in adult or paediatric nursing, it's quite scary to work with adolescents. People haven't had the opportunities for training and experience, by which I mean there aren't very clear pathways."

Nurse, discussion group (RCN, 2008)

### About this guide

This guide provides clear, accessible information to support nurses and other health care practitioners in their daily practice with young people. It was developed as a result of a survey that involved listening to nurses working with young people throughout England, Northern Ireland, Scotland and Wales.

### Who is the guide for?

This guide is designed to support all nurses and health care practitioners in their work with young people and to demystify the process. It may be particularly helpful for those who do not routinely work with young people.

We have chosen to use the word 'nurse' throughout the text to refer to a person who is an expert in the art and science of care. We recognise that nurses are often at the frontline of delivering care to young people, but they may also work in multidisciplinary services.

*Adolescence: boundaries and connections* aims to highlight practical tips that you can use in your daily work. It is written by nurses, for nurses and other health care practitioners. Each young person, and each clinical situation, is different, so this is not a definitive guide offering foolproof solutions. As well as using this guide, access whatever other information you can, watch how your colleagues work with young people and, most importantly, talk to young people about what works best for them. This way you can ensure that your learning is fresh and up-todate.

The guide is divided into eight sections, addressing the following issues:

- adolescent development
- building relationships with young people
- confidentiality
- consent
- supporting treatment concordance
- supporting relationships parents and peers
- recognising vulnerability
- local resources.

Each topic is further broken down into:

- a scenario or example demonstrating a nursing dilemma in this area of practice
- a summary of the topic in question
- key care principles, setting out the main points that nurses need to think about in relation to this topic
- practical tips, with ideas for how to apply the key care principles to daily practice
- · comments from young people who reviewed the guide
- further resources.

### Why adolescence?

This guide is intended to support the care of young people as they move into the adult world by recognising that adolescence is a social construct. We often think of adolescents as teenagers, but the World Health Organization (WHO) defines adolescence as:

...the period of life between 10-19 years, youth as between 15-24 years and young people, as those between 10-24 years. (WHO, 1989)

The WHO definition acknowledges the transitional nature of this life stage and the inherent variation between biological and emotional maturity and socio-cultural contexts. For children or young people with complex needs, even this age limit may be unreliable. For the purpose of this guide we consider adolescents to be any young person in a process of transition between childhood and adulthood. We use the terms interchangeably to reduce repetition of young person/people.

### A final word

The RCN Adolescent Health Forum is passionate about supporting the care of young people but recognise that at times working with young people can be challenging. We hope you find this guide a useful resource.

# 2. Adolescence:exploding themyths

### Teenagers are often shy of their bodies

Elise, who was 15, had been admitted to an adult surgical ward as an emergency with abdominal pain, query appendicitis. She was in unfamiliar surroundings, in pain and was frightened. When the doctors visited her, the students, nurses and doctors all stood round the bed. They wanted to examine her – she refused to let them, and one of the nurses told her off for wasting the doctors' time. Elise sulked and refused to talk to any of the nurses. They called her mother. Later she told her mum what had happened - her mum explained to the ward sister that as a teenager Elsie was shy of her body, Elise was also menstruating at the time, this shyness was normal and suggested that maybe just one female doctor examined her daughter or a doctor and a female nurse as a chaperone. The ward sister was extremely helpful and apologised for the incident, and said she would have a word with the nurse in question.

### What do we mean by adolescence?

Adolescence is a distinct developmental life stage that takes place between childhood and adulthood. The key changes during this period are:

- physical changes, due to puberty
- psychological change, such as forming a sense of identity and purpose, incorporating sexual identity, and developing new cognitive skills, including abstract thinking
- social change, including negotiating increasing levels of independence, and managing new levels of responsibility (for example, many adolescents are themselves carers).
  Establishing and maintaining positive personal relationships, including sharing and intimacy.

Adolescence involves moving from being a more dependent child to being a more independent adult. This means learning how to manage separation, choice, independence and loss, including the loss of childhood. How the young person's parents and other adults respond to them during this period can make a significant impact on their life. Previous childhood experiences can also influence young people's ability to grow through this stage.

### What's special about adolescence today?

Today, young people undergo these changes against a background of increasing and competing pressures from every angle, including school, work, family and sexual relationships. This often happens in the context of negative stereotypical images of young people in the media and elsewhere, which make many young people feel judged and misunderstood. These competing factors appear at a time when adolescents are already physically challenged by periods of rapid growth and sexual development.

### Why some adults find it difficult to relate to adolescents

In the UK today, there are many misconceptions about adolescents. Many adults find it hard to relate to young people, and want to categorise them and to treat them either as children or as adults. Even among those working with young people, awareness is often poor. Young people are not a homogenous group, so care needs to be taken when making assumptions about behaviour. Culture, faith, gender, family and intellectual differences all influence a young person's capacity to cope and grow.

Characteristics in adolescents that adults often miss, or find confusing include:

- a lack of confidence, a strong need for acceptance or a tendency to live in the moment
- a range of emotional responses to illness or distress that includes violent outbursts, non-communication or projected anger. Adults may find this behaviour challenging to respond to, but they may in fact be effective short-term coping strategies
- high levels of fatigue, often interpreted by adults as laziness – rapid physical change does lead to the body requiring more rest
- behaviour that appears surly, defensive or unco-operative, often results from a sense of frustration at being spoken to inappropriately – particularly being spoken to like a child.

### **Practice principles**

• Take a positive approach to adolescence. Rather than seeing it as a period of inevitable problems, see it as a time in which young people can build their resilience, with the right support and encouragement. Encourage the young people you work with to see their own strengths and uniqueness. Make a point of telling them what you like about them, even if they blush.

Young person's comment: Encourage young people to achieve the goals they have set or encourage them to improve the skills they already have.

- Remember that you, as the professional, are responsible for ensuring a positive interaction. Young people often find it easier if the adult asks pertinent open questions, as they find it difficult to talk about themselves. Ask them a direct question, for example: "Some people say they get stressed with exams/school work... Do you ever find that? What do you find helps with your stress?".
- Avoid making assumptions. A young person may not respond in the same way as an adult, or in the same way as another young person. Just because they seem okay or appear confident, it doesn't mean that they are. See the chapter on building relationships.
- Try to understand what the world is like for young people today. Taking an interest in their lifestyle. Appreciate the importance of makeup, clothes and music and social groups in forming an identity.
- Make sure any rules or regulations are fair. Young people need to know where they stand, but will be more likely to respect rules if they are genuinely set in their own best interests. Young people say they like adults who are fair and funny who understand that they (young people) will make mistakes sometimes, so ask adults not to over react. There are times when adults make mistakes too.
- Give young people a chance to trust and be trusted. Young people have little control over much of their lives. Give them the opportunity to take responsibility for themselves, and give them a reason to trust you – even if they don't trust the other adults they come into contact with.

Young person's comment: The jump to adult care is always difficult but by making support available, such as our MDT (Multidisciplinary Team) group, it becomes much easier.

- Bear in mind the particular difficulties for adolescents with chronic illness. Long-term illness may interfere with a young person's physical and social development, including processes such as separation from family. Moving from child to adult care raises a number of issues, for further guidance on supporting transition see Adolescent transition care (RCN, 2004) and Lost in transition – moving young people between child and adult health services (RCN, 2008).
- Bear in mind the particular difficulties for adolescents with learning difficulties or who are vulnerable due to their housing/social situation.

### Tips

• If a young person is missing their appointments, make sure that you set appointments at times that fit with their body clock or extra curricular activities, or arrange home visits/telephone/text to find out what's going on or what suits them.

Young person's comment: Check with them that they're not missing appointments for other reasons rather than just other activities 'cos they may have been wanting to tell someone but had never been given the chance.

- If you do need to make rules, emphasise what the young person can do not just what they can't. Ensure you start by saying: "We are here to help and listen, but need some rules to ensure (name) is safe for all who use/work here."
- Even if the young person appears confident, remember they may need a non-judgemental approach in supporting their decision-making.
- Protect young people's sense of dignity by being particularly sensitive when asking them to undress during ward rounds or medical examinations, as they can be very self conscious about their bodies, and make sure sanitary products, shaving equipment and mirrors are available.

Young person's comment: Ensure ALL curtains are shut – trust me, through personal experience it is not nice to undress – maybe if undressing is involved a woman doctor/nurse for females – a male doctor/nurse for males should be present?

• Help young people develop their vocabulary of feelings. If they only know words such as 'tired', 'bored', 'like' or 'hate' then this may limit their experience of their own emotions. If you're talking about potentially risky behaviour such as sex, drugs or alcohol, make it clear that while not condoning their behaviour, you're not judging it either. Just ask routine questions such as "how much do you drink?" or "do you smoke 20 or 30 cigarettes a day?" Once they realise they won't get into trouble for smoking/ drinking alcohol, they'll be more likely to talk openly about it. Then you may have an opportunity to discuss how they feel about their drinking/smoking etc. so you can advise them of alternatives and/or support available.

Young person's comment: Why not make a survey as some people find it easier just to write rather than speak about it.

- If you discover that the young person has other problems as a result of your conversation, recommend appropriate services to them and work out how they might get there. Help them plan the detail, who do they need to tell? How will they get the bus fare? Do they know exactly where it is? Do they have phone credit if they need to ring to make an appointment? Is there someone who can go with them for support? By offering to work through the detail you show you care.
- Remember that the first time you walk into an unfamiliar place, with unfamiliar people it can be scary so all health care spaces are potentially scary! When a young person has attended your service for the first time it's good to say "Thank you for coming".

Young person's comment: Direct questions are good but if they are personal direct questions then it can be embarrassing.

## 3. Building relationships

### Getting to know your patient

Mark, a 13-year-old, was admitted to Accident and Emergency following a fall out of a tree and sustained a fracture, later he was transferred to an adolescent bed on a children's ward. He was very withdrawn on admission and quiet, not making eye contact with anyone. He was allocated a nurse, Tom, who made a point of going over to chat with him during his shift, acknowledging that it must have been a shock for him being in hospital and being on a ward with Disney characters everywhere! Tom discovered Mark loved football so helped work out how he could watch a big game on TV that evening, using headphones. Later Mark told him he was embarrassed at falling and thought his friends would tease him if they found out. Tom worked out with him how he could handle this if it happened, working out the different options, including inventing a few humorous stories. Mark visibly relaxed on the ward and when he was able to move around was found playing monopoly with one of the younger boys. He said it reminded him of how he missed his younger brother.

### Why building relationships is important

When you are working with young people, building a relationship is a very important part of caring for them, even if you are only meeting them once. This is because a young person may not tell you what is really troubling them unless they feel safe and trust you. They may fear that you will judge them, misunderstand, or tell a parent or teacher and make their situation worse.

If a young person feels positive about their experience of your service, they are more likely to feel confident about returning to a health care service if they are troubled or unwell in the future. They are also more likely to recommend your service to a friend.

### What are my responsibilities?

We often think of relationships as a two-way process, but when you are working with a young person it is you, as the nurse or health care practitioner, who is responsible for building a professional relationship. Be proactive: young people can find it difficult to share their concerns, and if you don't give them time to let you know how they feel, you may never find out what is really troubling them. Respect young people by showing you are genuinely concerned about them.

### What if the young person seems unresponsive?

Building the relationship might feel like a struggle at first. The young person may appear sulky, silent, bored or aggressive – particularly if they feel angry or upset – and it may take longer to build a relationship with some young people than with others. If the young person has had negative experiences with adults in the past, they may have little faith that other adults will help them. Show a commitment to sharing the young person's care journey, even if they are rude or difficult. If you can remain calm and continue to offer support, eventually the young person will begin to trust you.

### **Practice principles**

- Make sure the young person is fully informed and involved. The first time you meet, introduce yourself clearly, explaining your job, what team you work in, why you're meeting them, how often you'll be meeting them, which professionals they might meet, and how they can contact you in the future. Try to give them the kind of information that they want, and check what they know already, so you don't state the obvious. Wherever possible, give them options.
- Use appropriate forms of communication. Pitch the language you use at the right level. If you're providing written information, check if the young person can read and that written communications use appropriate language. Use any of a range of communication strategies with young people based on their use of technology, including mobile phones, email and web resources. Make sure appointments and correspondence are handled sensitively in the way that suits the young person.

Young person comment: The guide tells nurses... times have changed for young people and we communicate in different ways to what they did when they were teenagers.

- Personalise any interaction with the young person. A degree of personal disclosure can help the young person to relax and open up e.g. you may talk about television programmes, music or sport.
- Take time to listen and empathise with the young person. A young person can easily tell if you really want to be there with them or not. Use active listening, and open rather than closed questions. Get a sense for who they are and their likes and dislikes, rather than focusing immediately on the reason they're in your service. Acknowledge that for them, this appointment may not be their top priority that day.
- **Demonstrate trust and honesty**. Be honest about the care and treatment you are providing, and any other considerations such as confidentiality. If you don't know the answer to something, admit it. If you are genuine and can be yourself, the young person is more likely to respect you, and they will feel that you respect them.
- Set boundaries to the care. Explain how you go about your job, what you can and can't do, limits to confidentiality and who else you will be sharing their information with. Explain your role and how this differs from a teacher, parent or friend. Explain how you can be contacted and what times you are available. If they want to contact you out-of-hours, suggest they use email.
- Make sure the environment is appropriate for the young person. Make sure first impressions are positive: think of small ways you can make young people feel at home, such as changing the name of the service, putting teen magazines in the waiting room, or producing a specially tailored leaflet. Consider working in non-traditional settings too. Outings and activities not related to their health condition may have as much impact as a session in the clinic.

### Tips

- Communicating appropriately doesn't mean trying to get 'down with the kids'! Try not to talk down to them, but equally don't expect them to act like adults or to understand medical language.
- Try not to focus on the specific language that a young person uses, even if it is unfamiliar to you or seems offensive. What matters is that they are trying to communicate to you. However, if a young person continues to use offensive language you may be able to challenge this in a non-threatening way.

For example: "Would you mind repeating that without swearing? I will not swear at you and want to help you."

• When you have explained something, check the person's understanding, and don't assume they will remember what you said a week ago.

Young person's comment: Acknowledge that first visits to services can be daunting. For example, say: "I appreciate you coming even though everything is unfamiliar/strange.

- Finding out one thing that the young person enjoys doing doesn't take long, but can make them feel important and special. Otherwise, break the ice by asking something like "did you watch *Big Brother*?" or use humour.
- Try not to ask a young person direct questions such as "how do you feel?", because this can feel invasive. Instead, encourage them to talk by asking: "Some people say they get angry when that happens does that happen to you?"
- Even if you do all the right things, be aware that a young person may not always give honest responses to some of your questions, so you still may need to go through issues just in case. For example: "You may not drink any alcohol at the moment but if you do then this tablet you are on may not work or may make you feel sick."
- As well as encouraging people to talk, give them permission not to talk. Remember if they are silent, they are not necessarily being unco-operative. They may need time to digest things.

## 4. Young people and confidentiality

### Ensuring a young person's confidentiality

Mary was 15-years-old when she was admitted with appendicitis. Her nurse needed to find out if she was pregnant before she went into theatre. Her mother is with her, therefore the nurse said: "I need to test your urine... can I take you to the toilet so I can test your urine?" In the toilet the nurse then asks her if there is a possibility that she could be pregnant. This gives Mary the opportunity to say whether she is sexually active or not, using contraception, and whether her parents are aware.

### What is confidentiality and why is it important?

Confidentiality is the principle of keeping secure and secret from others information that is given by, or about, an individual in the course of a professional relationship. Confidentiality is extremely important to young people. Breaking a young person's confidence can damage your relationship with them irrevocably.

### Young people have a right to confidential consultations

Young people under the age of 16 have as great a right to confidentiality as any other patient. If someone under 16 is not judged mature enough to consent to treatment, the consultation itself can still remain confidential.

### When should I break confidentiality?

In exceptional circumstances, you have no option but to break the young person's confidence – namely, if the health, safety or welfare of the young person or others is at risk (DH, 2003; GMC, 2004).

You would be required to disclose information in the following situations:

• if there is a court order – for example, if a young person

suffering from anorexia nervosa is at serious physical harm and refuses to eat or drink

- if it is required by statute for example, if a young person is being sexually abused by a person who they are living with and continues to be in danger
- **if it is in the public interest** for example, if a young person is threatening to harm or kill another person.

### **Considerations include:**

- whether the needs of the young person are the paramount consideration
- if the abuse or risk is current, whether the balance of risk shifts towards disclosure
- the developmental age and competency (in terms of maturity) of the young person
- what effect disclosure might have for example, if disclosing to the family might put the young person at risk in other ways.

### Before sharing information best practice is to:

- talk to the young person. If you have to disclose information, explain this to the young person, and tell them exactly what you will be disclosing, to whom, the reason and what will happen next
- try to get their consent, and keep disclosure to a minimum. Most importantly, make sure you justify your reasons for disclosure, focusing on how this choice will benefit the young person
- talk to your line manager or a team member about the disclosure to gain support and advice
- make sure the young person feels safe and supported throughout this process. This may require you to be with them as they share an event with their parents
- document all conversations.

### **Practice principles**

• Familiarise yourself with the safeguarding policies of your employers and professional associations. Explain your confidentiality policy right from the start. Inform the young person, and their family, that you operate a policy of confidentiality, and explain when this will be broken (usually if the young person or someone else is at risk).

- Only disclose information if this is in the best interests of the young person. The needs of the adolescent must always be regarded as of primary importance, as their age and vulnerability makes them powerless to protect their own wishes.
- Only disclose information on a need-to-know basis. This might mean that an agency needs to be told that sexual abuse has taken place, and by whom, but may not be told the details of the abuse.
- Only use the information for the purpose for which it is given. Don't use it for a different purpose without the express or implied permission of the young person.

### Tips

- Explain the confidentiality policy in a clear and reassuring way – for example: "It is safe to talk about anything with me but if I think that you may be at risk of harm I am legally bound to tell someone so that I can keep you safe."
- Be prepared to explain the reasons for your confidentiality policy to parents and or teachers/other care professionals.
- Consider a standard policy of seeing young people alone first so they can discuss their situation and any concerns in privacy with you before inviting their parent in to join you: "I hope you don't mind but I would like to be able to have a chat with your son/daughter privately."
- Discuss with young people how best to contact them in order to keep their information confidential. For example, they may prefer you to call their mobile rather than call on the parent's landline number, or to email appointment details through rather than writing letters.
- If you are in any doubt about whether to disclose information, consult your line manager, seek legal advice from the Nursing & Midwifery Council, the RCN, Central Service Agencies or other legal experts. Follow polices and procedures of the trust or authority you work for.
- Avoid accidental breeches of information e.g. in staff dining rooms, corridors or public spaces.
- Discuss with young people how others can breech their confidentiality e.g. if they have brought a friend with them to the consultation/clinic, how would they feel if they 'fell out' with their friend. Do make time for young people to be on their own with you as sometimes the person they are with, e.g. a boyfriend/girlfriend may not be as supportive as they appear.

## 5. Consent to treatment

### Gaining confidence and obtaining informed consent

Seema, a 15-year old girl, is admitted to a general medical ward having taken an overdose of 30 paracetamol tablets. Four-hourly paracetamol levels are required, but the patient refuses consent for taking blood or cannulation. If these steps are not taken the result will be liver failure and she is likely to die.

On questioning Seema about risk factors of not having paracetamol blood levels taken and reassuring her of why it was important she disclosed that she was needle phobic and was petrified. After lots of explanation and reassurance she eventually agreed to have bloods taken. Throughout the procedure she was supported and reassured. Seema then had the required treatment to reduce the effects of the paracetamol she had taken and was referred to Child and Adolescent Mental Health Services the next day.

### What is consent and why it is important

Consent means giving permission for something to take place. In health care, consent must also be informed. This means that the person not only agrees, but understands the full implications of what they are agreeing to, including possible side-effects, as well as potential benefits (Huband, 2000). Informed consent is a central principle of health care because it safeguards the rights of the individual to make choices about their health (Bijsterveld, 2000).

Obtaining consent from the young person is important, as it respects their right to self-determination. Occasionally parents or health care professionals take responsibility for giving consent when the young person is incapable of consenting on their own behalf.

### What is competency and why it is important

A young person is only entitled to give their own consent if they are deemed competent to do so. Competency refers to the young person's ability to understand choices and their consequences, including the purpose, nature and possible risks of treatment or non-treatment to be legally valid. The level of competency may depend on a range of factors, such as the patient's age, maturity, mental health, levels of intoxication or pain, and experience of the illness. A young person's level of competency may fluctuate, depending on what is going on for them at the time.

According to the Fraser Guidelines (1985) to assess a young person's level of competence you need to make sure they:

- understand the treatment offered and why it is proposed
- understand the main benefits, risks and alternatives
- understand the consequences of no treatment
- make a free choice, supported and without pressure.

If you are involved in assessing competency of the young person to consent, you should document this clearly. This should include recording the information given, the level of engagement and the person's level of understanding. For example: "The young person was able to describe the condition and reason for treatment." The more serious the procedure, the more important it is that the young person understands the implications of the treatment. Therefore it is essential that information is presented clearly, avoiding jargon and allowing time for reflection.

### Why do consent and competency cause confusion?

Confusion may arise when health care professionals are unclear about whether the adolescent should be treated as a child or an adult. A rigid approach to assessment can lead to some illogical decisions. For example, a young parent aged under 16 can consent to treatment for their own child, but is not seen as competent to decide on their own treatment. Similarly, assumptions about the young person's level of competency should not be related to whether they are treated on a children's or adult ward.

The test of maturity is therefore not age related but relates to an individual set of circumstances, so being under the influence of alcohol, certain substances, in shock or postanaesthesia may mean anyone, including a young person, is less able to be judged as competent. Therefore discussions about treatment that may have long-term implications are inappropriate at these times. Equally a young person who has had the ability to recognise they have put themselves at risk, say from unprotected sex, and sought advice from a primary care service could be argued to be acting in a mature manner. Research by Harvey and Gaudoin (2007) showed that teenagers were no less responsible about contraception than older women. So seeking advice and emergency contraception could be seen as a mature act, even if the full implications of being sexually active may not be understood in depth until later years.

### What about parents?

The Children Act (1989) says that, where possible, parents or guardians should be involved in the consent process. The young person's legal right to consent and confidentiality remain paramount. If the young person does not have sufficient understanding to make an informed decision, parents or guardians will consent to or refuse treatment on their behalf. In exceptional circumstances a young person under the age of 18 years, deemed competent, makes a decision that is not considered to be in their best interests, then this decision can be overruled by parents or the courts in England and Wales (DH, 2001). The notes below in *Practice principles* give information about Northern Ireland and Scotland.

### What is the nurse's role?

The nurse plays a vital role in supporting a young person to understand what the treatment, procedures or care may entail, which enables them to give informed consent. This may involve acting as an advocate, to support the young person through the consent process and ensure they have a voice in the decision making.

If a young person does consent to treatment, make sure that:

- they fully understand the potential risks and benefits of treatment, and the advice given
- they have considered telling their parents encourage them to do so if appropriate
- the treatment is in the young person's best interests
- there is no undue pressure or coercion to consent from either nurse, doctors or parents.

### **Practice principles**

• Article 12 of the United Nations Convention on the Rights of the Child enshrines the principle of self-determination, and nurses have a role as advocates for young people to uphold that principle where possible. Wherever possible, encourage the young person to collaborate and participate in any decisions around their care and treatment.

- By the age of 16, young people are presumed to be competent in law to give consent to surgical, medical or dental treatment.
- Under-16-year-olds can also give consent, but they are not automatically assumed to be competent, and competence must be proven. However, don't assume that consent for treatment of under-16s should automatically be given by parents.
- The consent of a competent child cannot be overridden by a parent or guardian. In some exceptional circumstances, if a child refuses treatment the parent or guardian may consent on their behalf, and treatment can lawfully be given. However, this should occur only rarely. For example, a 15-year-old is offered an immunisation as part of a school programme and they have received relevant information, have no medical contraindications and wish to proceed. If the parents refuse consent, the young person can still receive the immunisation and consent on their own behalf.
- Young people aged 16 to 17-years-old can give valid consent to treatment. However, if they are not deemed competent, the person with parental responsibility may take the decision for them. In England, Wales and Northern Ireland, young people aged 16 to 17-yearsof-age cannot necessarily refuse consent to treatment intended to preserve their lives or prevent serious harm. In Scotland, a competent young person may consent to treatment irrespective of their age (Dimond, 2005).

### Tips

- Listen. Encourage the young person to express their own views. Avoid being judgemental or making presumptions about their views or abilities.
- Give young people time to make decisions.
- When you or the team make a decision about a young person's competence, consider a wide range of factors rather than just their chronological age. The crucial thing is that the young person needs to have the capacity to understand their decision and the implications that this will have on them.
- When assessing competency, use formal guidelines such as the Fraser guidelines summarised in this section.

- Help the young person increase their level of competence, by empowering them to consider the options, and by giving them age appropriate information.
- If you have concerns that the young person's consent is not valid – for example, if you think they may have been coerced – discuss these with the multidisciplinary team.
- If a young person is refusing to give consent, make sure you take their views seriously. Adolescents are often labelled troublemakers or unco-operative – give them the opportunity to exercise their right to be heard.
- Encourage young people to involve their parents or guardians in the decision-making process, where appropriate.

### 6. Supporting young people through treatment

### Coping with treatment as a teenager

Joseph was diagnosed with type 1 diabetes mellitus at the age of nine. He is now 15-years-old. Since his diagnosis he has had numerous acute admissions with hyperglycaemia. In the past six months these have increased in frequency, and on two occasions he was admitted to the children's ward with ketoacidosis. He is fully aware of how to manage his diabetes but this is not a priority in his life at the moment. When he was admitted to the ward Joseph was placed on a sliding scale insulin regimen. The nurses took control of his diabetes while reassuring him that this could be seen as a "holiday from diabetes". Managing Joseph's diabetes meant that his nurses were then able to support him to do the same.

The support given to this young person was possible by taking a multidisciplinary approach, which included a:

- diabetes nurse specialist
- psychologist
- physician
- dietician.

The team helped the young person to understand that he can still have a young persons' lifestyle and learn to live with diabetes. This involved:

- discussing lifestyle issues such as: alcohol, substance use, smoking, exercise, sex, driving. For example, in this case the nurse explained that when Joseph began driving lessons he should always check his blood sugar prior to driving – if low he should move to the passenger seat and correct the hypo (dextrose tablet or orange juice)
- changing the insulin regime to fit in better with his lifestyle and to make it more flexible
- offering the young person and their family the support of a child psychologist
- continuing support after discharge through telephone contact, text, email and weekly visits.

Many young people find managing diabetes difficult during adolescence.

### Supporting treatment use

The terms compliance, adherence and concordance are used in health care to refer to a patients' ability to follow recommended treatment programmes. They are often used interchangeably, but compliance is considered authoritarian, particularly when we consider how to work with a young person to accept treatment plans. Concordance is the current preferred term because it suggests there is a reason for the difficulty, which requires exploration and understanding why a young person may find managing their illness challenging.

Types of challenges that young people may face include:

- turning up for their appointments
- taking recommended medication
- · avoiding alcohol while on medication
- · remembering to take medication regularly
- when lifestyle conflicts with medical recommendations
- appearing to be different from peers.

### Why a young person decides to discontinue treatment

It is not always easy to convince a young person coming to terms with adolescence to adhere to treatment. Apart from simply forgetting, there could be other reasons when a young person forgets treatment:

- fitting in with peers is more important than following treatment
- some treatments have strong side-effects that the young person may find intolerable
- if the young person needs to do something on a regular basis, such as do exercises or take medication, it may be hard to remember, or difficult to fit this in with their life style
- if medications are required during school
- the young person may be resisting treatment because they have unresolved feelings about the condition
- in chronic illness young people may find ongoing treatment relentless and monotonous

· lack of family/carer support.

If you need to talk to a young person about nonconcordance, it is important not to see them as troublesome or irresponsible, and to avoid using fear tactics. Only by gaining their trust and encouraging them to talk openly about their reasons for resisting the treatment can you help them find solutions to the difficulties, and encourage them to resume or maintain treatment.

### **Practice principles**

- **Remember to praise** the young person for the times they have remembered their medication, no matter how irregular.
- Take a consensual approach to treatment wherever possible. Engaging with the young person and understanding their needs is more likely to lead to practical solutions, which in turn will improve adherence.
- Respect the young person's decisions about their treatment and care – they have a right to selfdetermination. If the young person is not adhering to treatment, explain the safety issues and give them time to reflect on their decisions. Reassure them that you are available to listen and to continue the discussion.
- Advocate on the young person's behalf where necessary. In some cases – particularly for those who are chronically and terminally ill – you may need to advocate on the young person's behalf, and challenge the perceptions of others.
- Avoid making unnecessary demands. Try to avoid making young people do things just because it's generally accepted that they should be done. For example, getting out of bed or having a bath, or treatment at a time that suits the ward routine. Young people have very little say in many areas of their lives, so allow them to have control wherever possible.
- Avoid using scare tactics because they will not work if anything they will add to the feeling of 'what the hell, I'll do what I want now'. Developmentally, young people do not look at life and death or risk the way adults do, and often appear fearless about the future – hence the risk-taking label that accompanies adolescence. Telling a young person that good control of their diabetes will give them more energy to have fun is better than saying that blindness will result if their diabetes is not controlled.

### Tips

- Explain adherence issues from the young person's perspective. Humour can help. For example, if you want to encourage a young person with diabetes to adhere to their treatment, you could say: "You don't want to have a hypo when you're out with your boyfriend it can be a bit of a passion killer to say the least!"
- Make sure the treatment fits around the young person's lifestyle. If you need them to keep an appointment each week, make sure it's at a time of day that suits them, and that it doesn't conflict with something else that they'd rather be doing.
- Belonging to a peer group is vital for adolescents, as it offers a good source of support. If the person's reasons for not taking treatment are social, show the young person that you take this seriously and help them find ways around the problem.
- Keep the young person fully informed at all times about their treatment or care, any investigations needed, and any changes. Make sure they are actively involved in any decisions made in their treatment plan. Giving them a sense of power and control over their situation may encourage adherence.
- Take the steps described in Section 2 of this guide to ensure that the young person has positive relationships with the health professionals involved in their care at any given time, and make sure they feel able to communicate any concerns.

Remember rates of adherence to treatment in young people are similar to those of adults.

### 7. Relationships with parents and friends

### Assessing the situation

Claudia is a 15-year-old girl admitted to a specialist unit for chemotherapy. She is accompanied by her 17-year-old boyfriend and mother, and is very distressed and does not wish to be on her own. The mother has to go home to care for siblings and seems happy for her daughter's boyfriend to stay with her. Claudia becomes hysterical when one of the nurses suggests that her boyfriend leaves at 9pm because she wishes him to stay the night. Fortunately a senior nurse assesses the situation and speaks to Claudia and her boyfriend. It is clear that he has been of great comfort to her and both their parents are supportive of their relationship. He states he is happy to sit with her during the night and hold her hand until her mother can return in the morning when he will go home and rest. Claudia is relieved when the nurse in charge supports her request.

### Why parents and friends are important to young people

A young person's social networks play a major role in their overall wellbeing, and this includes members of their family and their peers. When you are working with a young person, it is important to get a sense of what things are like at home, and what their social life consists of. Seeing their situation within the bigger picture will help you develop a deeper understanding of what emotional support the young person has, any difficulties they are encountering (such as isolation or conflict) and how best to meet their needs.

### When a young person should be accompanied

Being alone in a new or unfamiliar situation can be frightening for a young person, so many young people will choose to be accompanied by a parent or friends for their appointments. Meanwhile, others prefer to maintain their privacy and come alone. Giving the young person a choice in who accompanies them can help them feel in control and provide reassurance in stressful or frightening situations.

### What should I consider when working with a young person's friends?

Peers, close friends and boyfriends or girlfriends play a vital part in a young person's support structure, and recognising this is an essential aspect of care delivery. A friend may accompany a young person as well as, or instead of, a parent, and their presence may be just as important.

Young people often have to cope with negative attitudes or misunderstandings about their condition among the wider peer group, so having a friend there who has a deeper understanding of what is going on may help them combat unsympathetic responses – such as accusations of being 'lazy' if their condition makes them feel tired.

If the young person wants their friend to accompany them to a consultation, explain that you cannot guarantee that the friend will keep their confidence, but that it is the young person's choice if the friend sits in. You may need to be flexible about normal visiting rules for a young person's friend or partner to stay with them overnight – try to consider each situation on its individual merits. Do not assume sexual activity is on the agenda, the comfort of a familiar person is important at all ages. During adolescence illness may lead to emotional regression therefore the presence of a parent or friend is essential for emotional support.

### What should I consider when working with a young person's parents?

Many nurses and health care workers find managing parental involvement tricky – particularly when it comes to who is present at consultations. This is because of the inherent tension between parental rights and responsibilities and adolescent autonomy. To address this, some services have a policy of only seeing young people alone, while others tend to include parents in consultations. An effective middle way is to see the young person alone first, and then to invite the parent in to join them later.

Bear in mind that some parents may want to be involved to an extent that is not helpful. Because of the power differential between most young people and their parents, many young people want to keep something from their parents. For this reason it is important to negotiate whether the young person should be accompanied, and to keep checking throughout the course of treatment. Nevertheless, avoid preconceived notions of the relationships between a young person and their parent. Although tensions are common, many young people actively choose to share their problems with a parent.

When you first meet a young person's parent, clarify what your role is, and set out your policies on confidentiality and consent. Explain that although the parent may not be involved in every step of the care, their support is vital.

Young person's comment: Why not allow the young person to enter themselves, to ensure they are involved, discuss any processes with them, then ask the parent to come in.

### How should I support the parent?

Your role may involve offering parents advice about how to support their son or daughter, or how to understand their behaviour – particularly for those with chronic conditions or disabilities, or following a major incident such as an overdose. Reassure the parent that their child's situation is not uncommon, and that relationships are fluid and have good and bad days, and encourage them to remain in contact with you if there are any questions.

If the parent is angry or upset during the consultation, it is important to acknowledge this and ask to see the parent alone for a moment. After discussing the issues with the parent, you may be able to mediate between both parties to explain how the other is feeling, and to support them in finding solutions to prevent further conflict.

### **Practice principles**

- Find out who the young person wants present at their consultations. There are a number of opportunities for doing this discreetly. Treat each case on its individual merits, rather than having a blanket policy based on factors such as age. Recognise that relationships are dynamic and do keep checking this out as poor relationships can improve.
- Be clear about confidentiality policies. You may choose to give not only young people but also their parents or friends alone time, so they can express their concerns.

• Focus the consultation at the young person, not the parents. If a parent or friend does accompany the young person, include them in the consultation, but direct all conversation predominantly at the young person.

Young person's comment: I think the guide is very good as it tells nurses that not all young people will want their parents to go along with them for consultations/treatment.

- **Respect a young person's decision not to involve parents**. However, take time to explore the reasons why with them – they may change their mind. In certain exceptional circumstances you may need to overrule the young person's wish, if you feel that their health is at risk.
- Make sure the young person's parents can be there if they want them. This is important even if the young person is being treated on an adult ward and this means being flexible in relation to visiting times. Young people when they are very sick or have been chronically ill for a long time require a great deal of emotional support and they should not have to face fear of the unknown alone.

Young person's comment: Why not mention something about friends and parents being allowed into the consultation through the letter you receive with your appointment – then they are aware beforehand.

### Tips

- When you are alone with the young person, try to engage with them on more general issues to build trust, before making a more detailed assessment.
- Remember a young person is often brought to appointments by parents or accompanied by a friend therefore you may have to negotiate seeing them on their own for the consultation.
- If a young person is resistant to you informing their parents about an aspect of their health or treatment, explore their fears with them.
- If you have to inform a parent about an aspect of care or treatment without the young person's consent, it may help if you can offer to help the young person explain the situation to their parents.

- Think about the correspondence you send out. Does it imply that parents will be involved? Does the young person receive personal appointment letters?
- If you find it difficult explaining to parents that they will not be present for the entire consultation, try putting it to them in a positive light. For example, you could say: "After the initial consultation, you might like the opportunity to see me too – would that be helpful?"
- Remember, the young person may have a number of reasons for keeping things secret from their parents. They may be visiting you to discuss their recent overdose, but if their parent is present they may spend most of the consultation thinking 'is she going to find out I smoke?'
- Do ask young people about their friendships and support networks. If a young person feels they have no friends or confidants this is a cause for concern. Developing friendships is a natural part of growing up this will require further exploration and guidance.

# 8. Working with vulnerable young people

### Spotting a vulnerable child

Ben, a 13-year-old boy, has been admitted with asthma and constipation, the nurses note it is only his father who visits in the evening. He has no clean clothes, and when asked about his family he becomes tearful and says his life is difficult at home. It transpires that he has had erratic attendance at school due to caring for his mother who is an alcoholic. This disclosure enables staff to refer Ben and his family to social services and to ensure a supportive plan is put in place.

### **Recognising vulnerability**

Most young people grow from childhood into adulthood successfully having developed resilience and a range of coping strategies that are a useful foundation for adult life. Adolescence can be a positive time of learning and development, however some young people face severe stress or are particularly vulnerable to harm.

Vulnerability means that a young person does not have the resources or support structure around them to protect themselves from harm. Vulnerability is multi-faceted so a child may be safe and appear happy and healthy then become vulnerable due to a change in circumstances. For example, the death of a parent or sibling coupled with a change in living situation could make a child vulnerable. However, not all children who lose a parent are vulnerable because the support structures around them, their preparedness for the loss and their ability to work through emotions may all lead them to cope and build personal resilience.

Certain anxieties such as diagnosis of a chronic or terminal illness or family trauma can add to a young person's vulnerability. Coleman (2002) suggests the following key factors to consider when assessing a young persons ability to cope with stress:

- internal resources
- support structure
- environmental factors e.g. stable home conditions, economic security
- severity of stressor and perception of stress.

### **Coping strategies**

Coleman discusses the gender differences in the development of coping strategies boys are more likely to use 'active-coping' and girls 'emotional-coping'. Withdrawal is deemed as a negative coping strategy and more common in boys. He suggests that those who work with young people should encourage understanding the types of stress, those that can be modified by our behaviour and those that can't.

He suggests the following coping strategies:

- 1. problem-focused strategies are good for anxieties that can be modified by our behaviour. A classic stress may be exams. A positive coping strategy for exams would be to learn problem-focused strategies to modify the stress such as revision, visualisation, and practice papers. Equally this could be used when a young person is due to have an investigation. They can be shown the room, have the investigation explained or talk to someone else who has had the test
- 2. emotion-focused strategies are good for stress caused by a diagnosis of cancer or diabetes. Talking through the roller coaster of feelings is important in these circumstances. For some young people a mixture of approaches can be used. A young person cannot be made to talk. However, this is where art therapists, youth workers and clinical psychologists can all play a role in enabling understanding.

Some young people though may be particularly vulnerable due to their disability, health or life experiences because of being:

- someone with special or complex care needs, or intellectual difficulties
- in specialist settings e.g. youth offending teams, prison health care, secure units, pupil referral units
- the main carer for siblings or parents

- displaced or separated from family due to war, a refugee or asylum seeker
- homeless
- · looked after or live in a residential home
- abused emotionally, physically and/or sexually
- a witnesses or victim of domestic violence
- have experienced severe trauma
- excluded from statutory services because they are from traveller or Gypsy families.

### Children and young people have rights

Children and young people have rights that must be upheld. These rights are protected by the United Nations Convention on the Rights of the Child (1989). This international treaty was ratified in the UK in 1991, and it sets out fundamental rights to which anyone aged under 18 is entitled. These include the:

- right to have their views respected, and to have their best interests considered at all times
- right to freedom of expression, and access to information concerning them
- health and welfare rights, including rights for disabled children
- right to health care and social security.

### Tips

- Under the Children Act 1989 the welfare and wellbeing of children and young people is paramount. Consideration in any decisions about a child's or young person's upbringing or treatment, and their wishes and feelings must be taken into account.
- Review assessment techniques to ensure vulnerable young people will be recognised.
- Ask the young people to describe how they cope with stress and who supports them and how?
- Notice what's missing e.g. a lack of visitors, gifts or cards or items that traditionally would be with a young person in hospital that demonstrate people care about them (clothes, poor dental care).

- Discuss different ways of coping with young people. Are these built into long-term care plans?
- Young people who are vulnerable need a voice, this requires nurses and other health professionals to be a strong advocate on their behalf.
- Recognise that young people who have witnessed or experienced trauma may take longer to trust adults. If they are emotionally closed it will take time and persistence to build a therapeutic relationship.
- Does your service have a list of other support services for young people both statutory and voluntary?
- Recognise that even though a young person may use English, this may not be their first language and an interpreter may be required. Be sensitive about the gender of interpreters, particularly if the young person has experienced a sexual assault.

## 9. Resources and further reading

### **Local services list**

The following table gives a list of suggested services that may be useful for you to be aware of locally. This is not exhaustive and services may vary in your area, so do check with your local council and primary care trust.

#### **Services**

Brook Advisory Centres
Child and adolescent mental health
Community paediatrician
Community children's nurses
Connexions
Safeguarding nurse
Sexual health services
r u thinking? (0800) 28 29 30
Social worker: emergency social services
Special needs liaison
Walk-in-centre

### Resources

There are many useful websites, and we list a number below. Remember, the Welsh Assembly Government, Scottish Executive, Department of Health, Social Services and Public Safety in Northern Ireland, and the Department of Health and Department of Children, Schools and Families in England maintain a range of up-to-date resources.

### **For professionals**

The following organisations contain a range of publications relevant to adolescent health. This is not an exhaustive list but gives a flavour of the support available.

#### **Adolescent Health Forum**

The Royal College of Nursing Adolescent Health Forum works with young people in a wide range of areas, including education, acute services and primary care. It promotes discussion and awareness of the needs of young people and those who care for them, and the development of appropriate services. http://www.rcn.org.uk/development/communities/ specialisms/children\_and\_young\_people/forums/rcn\_ professional\_forums/adolescent\_health\_forum

#### Association for Young People's Health

The Association for Young People's Health is a major new charity and membership organisation creating a focus for all professionals and organisations working in the field of young people's health. www.youngpeopleshealth.org.uk

British Medical Association www.bma.org.uk/ap.nsf/Content/AdolescentHealth

**Department of Health** www.dh.gov.uk

Department of Health, Social Services and Public safety in Northern Ireland www.dhsspsni.gov.uk

#### Directgov

A government website about health and relationships aimed at young people. www.direct.gov.uk/en/YoungPeople/ HealthAndRelationships/index.htm

#### **Every Child Matters**

www.everychildmatters.gov.uk

**Royal College of Paediatrics and Child Health** www.rcpch.ac.uk

Royal College of General Practitioners www.rcgp.org.uk

#### **Royal College of Psychiatrists**

A range of useful fact sheets relating to mental health issues and young people www.rcpsych.ac.uk

Scottish Executive www.scotland.gov.uk

Society for Adolescent Medicine www.adolescenthealth.org

**Trust for the Study of Adolescence** www.studyofadolescence.org.uk

Welsh Assembly Government www.wales.gov.uk

#### **United Nations**

For the full wording of the UN convention on child health. www.unhchr.ch/html/menu3/b/k2crc.htm

#### YoungMinds

YoungMinds promotes child and adolescent mental health and mental health services. It is also involved in consultancy work, training, and producing information leaflets. www.youngminds.org.uk

### For young people

After16 A website for young people who have an impairment or disability. www.after16.org.uk

#### **Arthritis Care**

Information about arthritis with a section aimed at young people. www.arthritiscare.org.uk/LivingwithArthritis/Youngpeople

#### Beat the bullies

Advice and help for school children and parents who are being bullied or suspect their children are being bullied. It also gives advice on drugs and their effects www.antibullying.org.uk

#### **Brook**

Provides confidential sexual health advice for young people aged up to 25-years-old. www.brook.org.uk/content/

**Bullying UK** An advice website. www.bullying.co.uk

**ChildLine** This is a free helpline for children and young people in the UK. www.childline.org.uk

### **Childrens Arthritis Trust (CAT)** A website that helps young people live with arthritis. www.c-a-t.org.uk

#### **Connexions Direct**

Connexions offers advice on education, careers, housing, money, health and relationships for 13 to 19-year-olds in the UK. www.connexions-direct.com

### Diabetes UK: Teenzone

www.diabetes.org.uk/Guide-to-diabetes/My-life

#### **Doctor Ann**

A general health information and health promotion website for young people. www.dr-ann.org

#### FRANK

The website provides a free confidential drugs information and advice service 24-hours-a-day for young people. www.talktofrank.com

### need2know health

Lifebytes and Mind, Body and Soul have merged to form need2know. It's a government-run teenage information website that gives young people aged 11 to 14 facts about health in a fun and interesting way. www.need2know.co.uk/health

#### Playing it safe

Sexual health information aimed at 16 to 24-year-olds. www.playingsafely.co.uk

#### r u thinking?

A website about sex and relationships aimed at young people. www.ruthinking.co.uk

#### **Teenage Health Freak**

General health information aimed at teenagers. www.teenagehealthfreak.org

Teen Info on Cancer (tic) www.click4tic.org.uk

### **Teens First for Health**

Health section with stories on health and life, lots of information about conditions and illnesses, from spots to bullying and chronic illness. Doctors advice in response to questions and problems. www.childrenfirst.nhs.uk/teens/health

#### there4me

An NSPCC online advice resource for children aged 12 to 16-years–old, who are worried about issues like abuse, bullying, exams, drugs and self-harm. www.there4me.com

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#### **Young Minds**

Mental health information for professionals, parents and young people. www.youngminds.org.uk

#### Youth Health Talk

The health information website has a collection of interviews with young people about their experiences of health or illness. www.youthhealthtalk.org

#### Youth2Youth

Youth2Youth (Y2Y) is a unique helpline service, run by young people for young people for all young people 11 to 19-years-old. The helpline is anonymous and confidential. www.youth2youth.co.uk

Helpline: 020 8896 3675 Monday and Thursday evenings 6.30pm to 9.30pm.

### **Further reading**

We have chosen a mixture of books and texts from academic to easy-to-read autobiography.

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Royal College of Paediatrics and Child Health (2003) *Bridging the gaps: health care for adolescents*, London: RCPCH.

Royal College of Psychiatrists (2004) *Surviving adolescence* – *a toolkit for parents*, London: RCP. A very practical summary of adolescence for parents that is also useful for all adults who work with young people. This is downloadable from the RCP website. http://www.rcpsych.ac.uk/mentalhealthinformation/ childrenandyoungpeople/adolescence.aspx

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