

# PALLIATIVE CARE FOR YOUNG PEOPLE WITH CANCER

**Rob George<sup>1</sup> and Finella Craig<sup>2</sup>**

1. Guy's and St Thomas' Hospital NHS Foundation Trust, London, and Department of Palliative Care and Policy, King's College London.

2. Great Ormond Street Hospital for Children, London.

Email: rob@palliativecare.org.uk

## Abstract

Adolescents occupy a world between paediatric and adult palliative practice. Here we consider what is particular to adolescence, that physical, cognitive and emotional change during which the adult identity is formed. Some patients will have been progressing through normal development before the onset of disease while others carry their diagnosis from childhood. For all, life-threatening malignancy challenges adolescent development and, equally, development influences how adolescents, families and professionals experience and manage their disease journeys. In writing, we are acutely aware of the differences between adult and paediatric practice, as well as the common ground. Adult clinicians focus on autonomy. Paediatricians are more aware of the adolescent as a child without the experience of independence. This may be crystallised as follows: we want young people to make decisions about their treatments and to be fully informed that they are dying; yet they still need parental permission to go to parties and to stay out late – and they quite possibly consider it completely reasonable for their mothers to choose and buy their underwear. The trick is to recognise and support the child with little experience of life as an adult, while at the same time facilitating their transition to an adulthood that may never be achieved.

***“The young...are full of passion, which excludes fear, and of hope, which inspires Confidence”.***

*(Aristotle, Rhetoric Book II)*

Young people with cancer are a small but unique group that cross adult and paediatric palliative care. The demands of symptom management are often complex, but perhaps no more so than in other age groups. In this commentary we wish instead to consider what is particular to adolescence, that process of physical, cognitive and emotional change in the transition from child to independent adult. It is an essential and unavoidable evolution during which the adult identity is formed. Some young people with cancer will have been progressing through normal development before the onset of disease, others may carry their diagnosis from childhood. For all, life-threatening malignancy will challenge key processes of adolescent development and, equally, adolescent development will influence how young people, families and professionals experience and manage the disease process.

Adult development is marked physically with puberty and biological changes. Attachments move from parents to peers, through discovery of self in the development and deepening of awareness, an internal thought life emerges alongside emotional and physical independence. It is usually completed as the teens turn into the twenties and culminates in one's new place and role as an autonomous but interdependent adult.<sup>1,2</sup>

The speed, success and challenges of this process depend intensely upon the individual and their circumstances, such as the way in which family and other responsible adults

support this transition. The challenge for professionals is to deliver palliative care while fostering and respecting the transition from child to adult and the challenges that this brings into each family's life.<sup>3,5</sup> Some patients will die before transition is completed, others will survive, but with adult identities built on very different experiences and principles to those of their peers.<sup>6,8</sup>

## Challenges of care

### ***New independence***

Young adulthood is a time when the relationship between parent and child starts to change rapidly as the young person seeks to find a lifestyle and identity outside the family. What is often regarded as 'challenging behaviour' is part of the essential process through which a young person explores their emerging sense of self. They discover and establish healthy autonomy and independence through experiments with diverse personal choices, lifestyles and values that are usually, and necessarily, different from those previously taught by their parents. Peer group identification and physical and emotional independence from their parents and family are crucial factors. Young patients face two conflicting realities – the drive and desire for independence from parents and family, competing with the need for physical and emotional support through illness from that very family from whom they are trying to separate.<sup>3</sup>

### ***New identity***

The defining characteristic of adulthood, in western culture at least, is that we are free – we have self-determination and self-government (autonomy) to pursue our goals and mould our lives as individual yet interdependent citizens.

But we can only learn and participate in this by experience and the opportunity to understand and assimilate the ideas of success and failure, liberty and responsibility.

Hope is an essential part of healthy and successful development.<sup>6</sup> The adult identity and autonomy that evolves through adolescence is crucially based on a certain sense of immortality that gives both the opportunity to determine and shape one's own future and the perception that any errors or risks on the way will be at worst a temporary irritant, but with no consequences of any note. "It will never happen to me" is the certain foundation that makes risk tolerable and extremes so appetising when the idea of a boundary or abyss into which one may fall, while possible, is never real in a personal sense. Adolescents from communities where premature death through violence is not unusual, may have a different perspective, yet will still engage in 'risk taking' behaviour. For them, the driver may be "what the hell" or "how much can I pack in" given that my time may be short. The whole point of experimentation is to learn what is safe and wise, however risky and whatever the environment.<sup>7</sup>

For young adults with cancer, the threat of death is real and present; the foundations of health, gathering strength, personal potential and an open future on which adult identity is built are shattered.<sup>8,9</sup> The future is not theirs for the taking, but is determined by external restrictions enforced by an unwanted and debilitating disease. Their future may never be realised and at best will be sculpted by limitations and loss, not aspiration or ambition.<sup>10</sup>

### **New affiliations**

Peer group identification is an early and essential medium for and determinant of adult identity. It is the way a young person starts to work out what sort of adult they want to be. They will choose a peer group that has an appearance and way of life that the young person wants to be a part of. They may change affiliations as their adult identity emerges, until they settle in one that suits in the short or long-term.

For the adolescent with cancer the demands of treatment restrict their freedom to socialise with a healthy peer group. School, parties and meeting up with friends are replaced by hospital admissions and days when they just feel too unwell to join in. Matched values, interests and appearance begin and may well end with how one looks and dresses. A teenager with cancer soon starts to look different from their peers – they may lose their hair, their weight may change, puberty may be delayed, they may have suffered some physical mutilation such as a central line, a naso-gastric tube or effects from radical surgery that cannot be hidden.

This separation extends beyond the physical – one cannot be part of a group socially or emotionally unless one can be immersed in its culture, attitudes, values and preoccupations. When facing cancer treatments and potential or inevitable death, young patients' priorities are pulled elsewhere, the conversation and goals of their peers, so often focused on fashion, fun and sexual relationships, often seem futile and meaningless in a world that has, for them, a new significance. Furthermore, it is

a painful reminder that one can never belong in the same way and that one's worth in the tribe, through young eyes at least, simply isn't there. Here is another dilemma – the tension of identification with one's illness and what it demands or with one's peers and what they hope for.

### **New restraints**

During the transition to adulthood, it is in early adolescence that a young person starts to travel independently, go out with friends, stay at home on their own and sleeps elsewhere. As soon as they may, they learn to drive motorcycles and cars or go backpacking. However, the young adult with cancer faces the opposite; they may be too unwell to go out independently, to be at home on their own, or they may even need help to wash, dress or use the toilet. The idea of any viable identification with a healthy peer group starts to vanish.

During adolescence, many young people start to find paid employment, giving them valuable work experience, as well as an income that is independent from their parents. For the young adult with cancer, ill health and hospital attendance make this virtually impossible. Independence from their parents, peer group identification and independent socialisation become even more difficult.

In addition, many families face financial difficulties while their child is unwell, because of consequences on parental employment and an overcompensation for their child's difficulties with expensive gifts, games and technology that achieve little other than more pressure on the credit cards.

Adolescence is a time of sexual development, sexual awareness and exploring sexuality. Much normal adolescent activity and discussion is focused upon it. Restricted independent access to a healthy peer group, anxiety about disability, attractiveness and physical ability for sexual activity or missed opportunities, can be a considerable source of concern for young adults with cancer. While they are unwell, their friends are finding partners, enjoying their first romantic or sexual encounters and moving on with their lives.

### **New powers, old restrictions**

Adolescence is a time when young people should start taking increasing responsibility for their own lives (practical autonomy), weighing up consequences and making decisions. Many of the choices and decisions faced by healthy adolescents are 'safe' in that they are unlikely to have long-term irreversible and detrimental consequences. While it is appropriate that a young adult with cancer is also involved in making decisions about their own life, the type of decisions are very different from those of normal adolescence. There is no easily accessible place to find views outside family or the professionals around them unless their care is in a unit devoted to and geared for such transitional care. That said, there are increasing resources on the web through sites such as [www.canteen.org.au](http://www.canteen.org.au).

The development of adult capacity and the skills to make decisions under normal circumstances begins gently and occurs within the family and other social settings that are by and large free from outside eyes. Our patients

have experience of healthcare, treatments and their consequences. Some may have the capacity to decide and determine how much they are to know of their illness and its prospects, but many may not have fully mature adult reasoning processes and coping mechanisms. Once healthcare becomes involved, the delegated duties of society lock in and young patients become subject to formal definitions of adult and child that have profound effects on their liberties depending upon which side of their 18th birthday that they lie. Even though the adolescent may have a very developed technical and practical understanding of their illness, there is a very real risk that the decisions are taken primarily by the family and clinicians.

The motivations and desires are to protect and to ensure that mature minds consider consequences or factors that a developing personality may discount or misjudge, but they fail often to see that maturity and adulthood don't automatically bring infallibility in discerning someone else's best interests and that incomplete understanding automatically excludes one from the decision making process. The price may be a patient denied the opportunity to choose how to spend the time they have left.

The professional must facilitate opportunities for the young adult to be fully informed about their disease and prognosis, but must also be aware that few teenagers will have a robust adult identity, values and coping mechanisms. Some will not want to be fully informed of their prognosis or be involved in making decisions and will devolve responsibility to their parents as their way of coping.

## **New doubts**

One generic characteristic of humans is the need to find causes and explanations for events. It is not unusual for a young person to question, challenge or reject their family's belief system. This may be the desire to be independent in thought, or because they must test its robustness and utility in times of need.<sup>11</sup> The young patient may ask the direct and personal questions about why this is happening to them and the meaning of their life. This may become more urgent as time passes.<sup>12,13</sup> Patients may respond in one of at least three ways:

- Regress back to helpless childhood and transfer all responsibility on to family.
- Rail against all things parental and ferment with anger, since one's peers cannot begin to understand.
- Explore spiritual questions and belief systems that the healthy are able to defer to their mid-life crisis or retirement.

This crisis may extend to other members of the family and may need more extensive support. It can also be a source of considerable anxiety when death is imminent.

## **Approaches to care**

### ***Palliative care for young people***

Palliative care is a practical philosophy that assists patients

and their families to engage and transcend suffering and to bring some control and perspective to the uncertainties that are part of progressive disease. However, it is relevant to all stages of disease and is most effective when integrated fully into oncological practice.<sup>4,12,14-16</sup> Supporting young people to continue the transition to adulthood and to achieve as many realistic goals as possible requires flexible, responsive and tailored care rooted in open, effective communication and partnership with the patient and their family.

Palliative and end of life care can only make meaning of suffering and uncertainty if it is directed to facilitating the means and opportunities to complete outstanding tasks, resolve relationships and achieve some personal resolution. The elements of our practice – symptom control, psychological support, care packages etc are our tools – the means to this end, rather than just simplistic ends in themselves. They should concentrate ultimately upon creating those opportunities for choices to be made.

### ***Involving young people in decisions about their lives***

As for anyone, creating decision space for young people is the real objective of palliative care.<sup>17</sup> This is the opportunity to make realistic choices and achieve realisable goals, unimpeded as far as possible by physical, emotional and spiritual distress. Openness and honesty are paramount, but must be sensitive. While all young people have a right to be fully informed, some may not want this information, or want to guide the pace at which it is received; parents may want no disclosure at all. But this is only a short-term advantage to clinicians that presupposes that the patient is unaware of what is going on. There is no evidence to support this.<sup>15</sup> Conversely, distress will inevitably come from helplessness compounded with fears and anxieties that gain size and significance if left to the imagination, rather than being tested against evidence and truthful dialogue.

1. Young adults should have the right to opt out rather than having to earn the privilege of opting in to discussion.
2. If a patient is capable, we take what they say. If they are incapable, then we attempt to maximise that capacity, and in whatever state they are, we should act as far as possible in a way consistent with their wishes and values as far as they are known.<sup>18</sup>
3. Open, honest communication with the young person and their family must begin in the first meeting.
4. It can be helpful to discuss with the family at this point how they would like to receive information – as a family group or individually. It should also be possible to ask the young adult, with the parents present, how much information they want to be given, who should give it to them and who should be present, even if it is difficult and distressing.

This approach will often require careful negotiation with parents to assure them that their child will be given information sensitively and at an appropriate pace and timing. Parents will need support and guidance, as they

will need not only to deal with their own grief, but that of their child and siblings.

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

One of the most crucial elements to build adult identity is peer group identification and interaction. As discussed earlier, young adults with cancer will find it increasingly difficult to identify with healthy peers and we need to optimise their ability to do this.

1. School attendance should be encouraged and supported.
2. Treatment regimes should, where possible, be organised around important social events such as a party or a school trip.
3. Interaction with other young adults with cancer offers an alternative and is important to create a safe space where they really do fit in and become one of the crowd.

Many young people will continue to have ordinary adolescent plans and wishes for the future, even when they know these will not be realised. This can sometimes cause confusion among professionals and parents, who interpret these dreams as 'being in denial' or fear that the young person does not understand that they are going to die. A skilled professional will be able to acknowledge and respect these dreams, while maintaining honest communication and avoiding false reassurance. It is important to balance unachievable goals with goals that can be realised, however short a life may be.

4. Professionals should support young adults to achieve physical independence from parents through arranging home adaptations and appropriate aids in the home.
5. Parents should be encouraged to allow their young adult to go out and socialise with friends, not hold them back because of their illness.
6. Those who are too unwell or disabled to go out with friends independently, should have access to a carer or youth worker who can assist them – bringing a youth worker or carer may be less embarrassing than bringing a parent along. Opportunities to go out with other young people with cancer or disabilities should also be facilitated. These may be organised through a young people's cancer unit or hospice and enable socialisation independently from parents, but with adult support available.

### **Psychological and spiritual support**

Many young adults with cancer do not face the future of endless possibilities embraced by their healthy peers. There will be restrictions – real or potential – even for those who survive: 'Will I be fertile; will I be attractive; will I get the exam grades I need ...?' Those who face death will grieve the things they will not achieve: 'I will never get

married; I won't have my own home; I won't have children; I won't learn to drive ...'

They require opportunities to explore their feelings, without fear of upsetting other members of their family or carers. They need the chance to be angry, to ask "why me?" and to explore some of the ways in which they can bring meaning to these questions and their possible answers.

1. It is essential to provide time and space for young adults to express their fears and concerns, to have these acknowledged and to be supported through their grief.
2. Opportunities to socialise with other young adults in a similar situation will facilitate the development of peer support, but we must also provide opportunities for individual and group support from professionals experienced in working with young adults.
3. The whole family should be able to access appropriate psychological support, both individually and together.
4. The needs of siblings must not be overlooked and they should have the opportunity to take part in activities with other siblings (for peer support), as well as receiving individual attention.

Many young people will want to explore and question their spiritual beliefs and chaplaincy that is capable of addressing the diversity of faiths and belief structures must be a core part of every palliative care team.

### **Teamworking**

Interdisciplinary practice is the only way in which to meet the holistic needs of the patient and their family. Shared care with primary care, local paediatric or adult services (where appropriate) is essential, as they have the skills and necessary local relationships. It is frequently wise also to continue close joint work with the oncology team. It has generally been our policy to see younger patients at diagnosis and begin developing a relationship and trust. While it is generally agreed that young adults with cancer should be treated in units dedicated to this age group, there are common values, characteristics and skills that all teams and services should enshrine and cultivate to ensure that the needs of their patients and families are met.<sup>19</sup>

As with palliative care in general:

1. A clear, working understanding of the nature and purpose of specialist palliative care, especially from the point of view of:
  - a) its scope
  - b) flexibility
  - c) responsiveness
  - d) the basis of why we do things.
2. Advanced communication skills should be developed in all practitioners, including those whose focus is acute care. They should be capable of working:

- a) Across age groups and generations – families' active caregivers may include siblings, parents and grandparents. They see the world very differently.
  - b) Across social groups – a family living on social benefits may have very different needs to a family with two working parents; each will have different advantages and disadvantages.
  - c) Across cultural groups – there are some very strong traditions and ways of dealing with illness that must be respected and accommodated in care. We have been speaking of the western democratic model of autonomy that is not shared by many in the world.
  - d) Across religious groups – for some, an acceptance of inevitable death from illness represents a rejection of faith.
3. Identification and assessment skills to spot and refer appropriately for:
- a) specialist psychological assessment and support
  - b) pastoral and spiritual care
  - c) technical care from the spectrum of specialist practitioners such as occupational or physiotherapy, speech and language and dietetics.

This requires necessarily that all clinicians should have a working knowledge and basic skills in the specialities of the team. This is what we mean by interdisciplinary practice.

### **Breaking our perception and taboos**

- 1. Truth with colleagues and others is a central tenant of good care and should never be compromised.
- 2. As professionals we cannot make everything alright. Baggage in a family will accumulate around an ill member and may have nothing at all to do with a patient's cancer or their death.
- 3. Overcome the mutual views that separate paediatrics from adult care – both groups have valuable things to bring to the child in transition. To keep them in childhood is negligent, but to pass them on to adult practitioners without appropriate transition is equally unacceptable. The interdisciplinary care needed for this group and the packages of care and support needed require adult and paediatric services to work as a team in a focused way for each individual.
- 4. Work in a team requires the active involvement of all players and their being prepared to debate, disagree and dissent as cases are managed. Many views will get the team closer to what is needed and the tension this may generate can be a sign, not of poor teamwork, but of a strong team.<sup>19</sup>

- 5. Allow crises and emotions, but encourage responsibility in using them to move the patient forward. It is not the upset itself that is to be avoided, it is the remaining in it.
- 6. Don't be problem orientated, be problem solving. Analyse all interventions on an objective assessment of benefits and burdens; the more difficult the decision, the longer it will take to decide and often the more people who need to be involved. It doesn't matter how long it takes to decide, what matters is that the best decision is reached.
- 7. Anything goes as long as it has purpose and potential to move the person on in their conclusions.
- 8. Everyone in the biological and social family is part of that team and is entitled to support and care in their own right. It is a very good idea for there to be regular reviews of care to which everyone is invited.

### **Conclusion**

Adolescents occupy a world between paediatric and adult practice. In writing this paper, we have become increasingly aware of the different approach and emphasis of the adult and paediatric clinician, as well as the common ground. The adult clinician may focus on the autonomy of the young adult, while the paediatrician may be more aware of the young person's role as a child, who has never yet experienced life independently from their parents. The conflict between the child and adult worlds the young person lives in is highlighted when we consider the following – we want the young person to make decisions about their treatments and to be fully informed that they are going to die, yet they still need their parents' permission to go out to parties and they still need to come home at the time their parents tell them.

The challenge of palliative care for young adults is to recognise and support the child with little experience of life as an adult, yet at the same time facilitate their transition to an adulthood that may never be achieved.

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