

Palliative Care for Young People Aged 13 – 24

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on behalf of the Joint Working Party
on Palliative Care for Adolescents and Young Adults

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The Joint Working Party on Palliative Care for Adolescents and Young Adults

Established by:

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The Scottish Partnership Agency for Palliative and Cancer Care.

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Terms of reference

To consider evidence on the care of adolescents and young adults requiring palliative care and to publish guidance.

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" Everything stops at 18.
Everything is a battle"

Foreword

The period of time between childhood and becoming a fully independent adult can be a challenging one for both those growing through teenage years and their carers. The addition of a life-limiting illness adds a complexity that hardly bears thinking about. Children and adults with life-limiting illness have had their palliative care needs at least thought about, and in many cases provided for. This report provides a guide to what can and should be done to help the 'in between' group. It is especially important as the opportunity was taken to involve a relevant reference group of young people in its production.

Better supportive care for conditions which manifest in childhood means that there is an increasing number surviving into the transitional years and, therefore, there is a real need for improved and expanded services. The needs of young people at this time are very different from those of children and adults, and special thought needs to be given as to how to provide for these.

This report is not prescriptive about how services should be provided but sets out principles, which all members of the caring team can adapt to local needs.

The previous reports and work of the three partner organisations have already contributed much to help children, adults and their families. Their joint Working Party, along with the very important input of the young people's group, has produced a document of which they can be proud. There are important messages for many different professional groups from both statutory and voluntary agencies and we hope not only will the guide be widely read, but action will follow.

This report should help these young people to make the best of living even if their lifespan is limited.

Professor A.W. Craft
Honorary President of ACT

Executive Summary

- This study concentrates on the care and support needs of young people aged 13 to 24 with life-limiting conditions, who require palliative care. The definition of palliative care was taken from the ACT/RCPCH Guide to the Development of Children's Palliative Care Services (1997), which includes physical, psychological, social and spiritual aspects. Detailed discussion of symptom management, bereavement support and the care of young adults with children of their own are not included.
- An expert Working Party was convened to consider evidence. Only limited research was reported in the literature, and the Working Party relied heavily on written and oral submissions from a wide spectrum of respected professionals from many disciplines and voluntary organisations in both adult and children's sectors. Most of this evidence was opinion, based on clinical evidence, experience and descriptive studies. A Young Persons' Forum supplied the views of the young people themselves.
- These young people have a wide spectrum of diseases and disorders, some congenital or genetic and apparent from a young age, others contracted in childhood or adolescence. The annual mortality rate for this group is 1.7 per 10,000 young people aged 13-24. But there is a much higher prevalence of young people living under the threat of death who require symptom management and daily care. We estimate they number between 6,000 and 10,000.
- The numbers of these young people will inevitably grow, since earlier diagnosis and improved techniques and management are leading to high rates of survival. Many young people with chronic progressive conditions reach a crisis in terms of physical deterioration in adolescence or early adulthood. Many die in their late teens or twenties.

- The needs of this age group are specific and different from both children's and adults'. Development continues in physical, emotional, social and cognitive spheres leading to the expectation of independence. At the same time, the onset of acute illness or progressive physical or intellectual impairment causes isolation and dependency. Young people with severe intellectual impairment have additional special needs.
- Although young people with cancer are often provided with adequate services, there are many young people with other conditions who are not and whose needs are equally great. There are two wide groups: those who are developmentally intact and those with severe neurological impairment.
- Many of the disorders were formerly limited to childhood and there is insufficient expertise in the adult sector. This causes anxiety and uncertainty in the transition procedures and dissatisfaction with the services provided in the adult sector. There are particularly difficult issues for those whose transition coincides with fast deterioration and the expectation of the need for terminal care.
- We have investigated current provision and a thumbnail sketch is given in Appendix 1. We have found the provision complex and very varied. An assessment of local service provision will be a pre-requisite in any planning process.
- There is a huge gap in the provision of respite care for this age group. Many young people continue to be cared for at home by their families, but facilities for respite away from home and which include nursing care are scarce.
- The psychological needs of this group are not being addressed adequately. Young people facing their own death need opportunities to explore their feelings without fear of upsetting other members of their family. Depression in this group is not uncommon. Descriptive evidence from cancer units, children's hospices and voluntary organisations shows that bringing young people together for treatment or recreation can be supportive.
- Flexibility and choice in service provision emerge as important principles, with the young people making decisions whenever possible. Independence and aiming for personal goals are important, but deteriorating physical health and mental faculties may make this a challenging prospect for families and professionals.
- There is a shortage of professional staff trained to meet the palliative care needs of this age group. The current educational programme is inadequate for comprehensive training on a multi-disciplinary basis.
- Work with young people with life-threatening conditions can be emotionally draining and a formal support and supervision system is necessary.
- The Working Party feels strongly that planning flexible provision, with an emphasis on separate and differing needs, rather than on separate services is essential. It is considered that the allocation of major new resources may not be necessary, but rather that some needs could be met by the expansion of existing services.

Recommendations

These are the major recommendations of the Working Party. Other helpful information, such as principles for care and service components is given in the Concluding Guidance.

1. Young people with palliative care needs should be recognised as a distinct group with physical, psychological and developmental needs that are significantly different from those in children and adults. Palliative care strategies should take into account the wide range of disorders that cause the distress and eventual deaths of young people.
[Section 2.2 and Chapter 3]
2. Involvement of young people in decision-making, continuity of support and anticipation of needs are important principles that should be central in the planning and provision of care.
[Chapters 5 and 6, especially Sections 5.7, 5.12 and 6.3]
3.
 - a) Those responsible for commissioning services should carry out a local needs assessment for their population of young people with all types of life-threatening conditions, including consultation with the young people themselves.
 - b) Commissioners should include and define specifically the care of young people when developing their obligatory palliative care strategies. Strategies should include provision for long term continuing care for those who need it.
[Sections 2.2, 2.3, 5.3]
4. Services for young people with palliative care needs should be multi-disciplinary and multi-agency. Flexible provision, with an emphasis on separate and differing needs, rather than on separate services should be considered:
 - a) In the community, there should be a service for young adults over the age of 18, similar to the paediatric community teams that care for children with life-threatening disorders, or based on the rehabilitation teams that have been piloted. *[Section 5.1]*

- b) A named key-worker is essential to ensure that appropriate input is provided and monitored for each young person and their family. The person holding this position may change over time. *[Section 5.2]*
 - c) The role of professions allied to medicine, especially physiotherapy and occupational therapy, should be clearly identified and resource needs made known to commissioners. *[Section 5.5].*
 - d) A proper system of purchasing, maintaining, replacing and upgrading of aids and equipment should be in place and monitored. *[Section 5.12]*
5. Consideration should be given to the appointment of a 'link worker' to co-ordinate the range of services and providers, including the voluntary sector, on a district or regional level, in contrast to a key worker who concentrates on an individual person's needs. *[Section 8.4]*
 6. Health and Social Services should formulate joint plans urgently, based on a pooled budget, for respite care both away from home and within the home, taking account of any physical and intellectual impairment of the young people concerned. *[Section 5.3]*
 7. Clinical psychology is essential in all palliative care and particularly critical at this developmental age. It should be included as a core service in all care plans rather than as crisis intervention. Attention should also be paid to the needs of siblings, parents, partners and significant others. *[Sections 5.4, 5.9]*
 8. All young people need to explore spiritual issues and all front line staff should be prepared to provide this support or alternatively to identify another person with an understanding of young people's needs. *[Section 5.8]*
 9. The transition from children's to adult services should be given urgent attention. Providers should initiate early planning, so that a detailed, multi-disciplinary plan agreed with the young person is in place by the time the young person has reached mid-teens. *[Chapter 6]*
 10. More adult consultant physicians should develop expertise in the care of young people with rare conditions. *[Section 3.4]*
 11. General practitioners and primary care teams should aim to become better trained in palliative care and in supporting their young patients in the transition from paediatrics to adult services. *[Sections 5.2 and 6.3]*
 12. All providers of palliative care for this age group should ensure that their staff (including ancillary staff) are trained to work with young people. The educational programme needs to be expanded to provide a more comprehensive training on a multi-disciplinary basis, to counteract the shortage of professional staff trained to provide the palliative care needs of this age group. Resources need to be identified for education in this field. *[Section 7.2]*

1. Introduction

1.1 Aims of the project

- To identify the palliative care needs of young people with life-threatening conditions.
- To collect evidence on how these needs are currently being met.
- To make recommendations, which may include specific guidance or the need for further study.

1.2 Methods

An expert Working Party was convened and met over a period of 15 months to consider the information available. During this time five meetings were held. The researcher and the project co-ordinator were also members of the Working Party and carried forward the work between meetings. Following a literature review and search for data on morbidity and mortality, the Working Party took written and oral evidence from young people, parents, families and professionals from a wide spectrum of disciplines and voluntary organisations who work with this age group, receiving more than 120 submissions. Additional information on the involvement of the adult palliative care sector was also received from a sample of 18 adult hospices, which were selected randomly.

Every opportunity was taken to gather the views of young people (or their parents and carers when verbal communication was not possible) either directly or from the literature. The Young Persons' Forum was made up of seven members. On account of illness, the forum met only once, but it continued its discussions by mail and e-mail. The section on needs is based on the views of the forum, supplemented by the opinions of ten other young people, whose views were recorded in the literature. These 17 young people had a wide spectrum of life-threatening conditions, including cancer, congenital heart disease, cystic fibrosis, duchenne muscular dystrophy, muscular atrophy, neurological and metabolic disorders.

Much of the evidence drawn on for this report has come from respected professionals in the field who have shared their experiences with us. Most of this evidence was opinion, based on clinical evidence and descriptive studies (Higginson 1995). In our literature search we found very little on the palliative care needs of young people, especially young adults (18 to 24). In Department of Health and relevant voluntary sector documents, they are rarely mentioned. The considerable literature on adolescent young people concentrates on health promotion or on independence and rights for young people with disabilities. Most useful were a review of young people in hospital (Viner and Keane 1998) and a recent workshop on transition (Kurtz and Hopkins 1996), which brought together relevant material.

A draft of the report was sent out for consultation to 65 individuals and professional and voluntary organisations, and 42 responses helped to shape the final version.

1.3 Notes on terminology

Following a search through the literature, the Working Party decided to use the terms 'young person' and 'young people', which are increasingly employed in relation to this age group in documents from the World Health Organisation, the UK Government, professional bodies and the voluntary sector.

The WHO wrote in 1989

"Youth is a period of transition from childhood to adulthood, marked by interlocking changes in the body, in the mind and in social relationships. From being simple, function and behaviour become more complex. The body develops in size and reproductive capacity and becomes more sexually defined, the mind becomes more capable of abstract thinking, foresight and internal control and acquires greater awareness of the environment; and the close relationship with and dependence upon parents and older family members begins to give way to more intense relationships with peers and adults outside the family as new challenges are met and new responsibilities assumed." (The Health of Youth. Background document. Technical Discussion, May 1989).

This does not give any age boundaries, though elsewhere in the text it says:

"Chronological definitions are statistically convenient, but there are variations in timing and duration."

We have avoided the term 'teenager', which is not used greatly in the professional literature and has a connotation of 'pop culture' attached to it and hence may be pejorative. Similarly we have avoided 'adolescent' which has an implication of "still developing, not quite complete yet" and hence could be humiliating and unacceptable to some young people. However, 'adolescence' is a very useful medical and developmental term used in many scientific articles and professional reports and we use it occasionally in this context. The literature describes it variously as stretching from 10, 12 or 13 years to 18, 19 or 24 years. Occasionally we use the term 'young adult' to describe young people in their early twenties who are taking on independent responsibilities.

1.4 Exclusions

We have concentrated on the care and support needs of young people with life-threatening conditions, using the ACT/RCPCH definition from the *'Guide to the development of children's palliative care services'* (1997) (see Section 2.1). Readers are advised to consider this report in conjunction with that document, since we have tried not to duplicate material and much in that report is relevant. Detailed discussion of symptom management has not been included due to the wide range of conditions affecting young people. Bereavement care is also excluded as there is a large body of literature already in existence.

While carrying out research for this report, we have become aware of young adults over 24, with a range of diseases, who themselves have young families. In their case a wider range of issues have to be considered and we have not included these in this study.

2. Background

2.1 Palliative Care



Palliative care for young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the young person and support for family and friends and includes the management of distressing symptoms, provision of respite and care through death and bereavement¹.


The term 'quality of life' is central in this definition. Recent discussion of the concept implies a meaning that links expectations to realisation. The expectations, of course, are affected by life experience, developmental stage, socio-economic background, ethnic background and other variables and are totally individual. For this age group, expectations are often linked to the development of independence, a major goal in adolescence and early adulthood. The idea that a care package should be tailored around the enhancement of the quality of life underlines the importance of communication and aspects of this are expanded in Sections 4.1 and 5.7.


The time scale for palliative care for such a wide variety of conditions varies enormously, varying from a few days to many years. The relationship between curative and palliative care is highly variable within, as well as between, conditions.


¹Documents used in the development of this definition are listed at the beginning of the References


Curative and Palliative Care Relationship

Key  Curative  Palliative

 As the illness progresses the emphasis gradually shifts from curative to palliative treatment.

 Highly technical invasive treatments may be used both to prolong life and improve quality alongside palliative care, each becoming dominant at different stages of the disease.

 No cure is possible and care is palliative from the time of diagnosis.

 At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation dawns.

2.2 Who are we including?

2.2.1 Nature of illness

We include young people who will die prematurely as a result of the life-limiting nature of their illness or disorder. Some will have lived with these conditions since birth or early childhood. Others may have contracted the disease in their teens or early twenties. In some conditions, the young person will remain mentally alert. In others there is a progressive intellectual deterioration. Most will fall into one of the following groups (based on ACT and RCPCH 1997):

Young people with life threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. Young people in long-term remission or following successful curative treatment are not included. Examples include cancer, irreversible organ failures of heart, liver or kidney.

Young people with conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, but premature death is still possible or inevitable. Examples include cystic fibrosis, Duchenne muscular dystrophy, HIV/AIDS.

Young people with progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples include Batten disease, mucopolysaccharidosis, CJD.

Young people with severe neurological disability which may cause weakness and susceptibility to health complications. Deterioration may be unpredictable and not usually progressive. Examples include severe multiple disabilities following brain or spinal cord injuries, severe cerebral palsy.

These four groups are described as a guide to the young people who are likely to have palliative care needs and the categorisation is important for the purpose of planning and needs assessment. However, it is not suggested that all young people in these four groups need active palliative care throughout the trajectory of their disease or condition. Some, for example those in the second group, may have long periods of relatively good health. Others in that group may be more vulnerable and may need active palliative care at an early stage. Individual needs assessments are therefore an important part of the palliative care process.

2.2.2 Age boundaries

Defining this group is problematic. We have taken the ages of 13 and 24 as the lower and upper boundaries for our study, with the intention of covering adolescence and young adulthood. However there is really a continuum, with the needs of children evolving into the needs of young people and again into the needs of adults. We recognise the need for flexibility and do not intend to be prescriptive. Young people with cystic fibrosis, duchenne muscular dystrophy and juvenile Batten disease, for instance, increasingly are surviving beyond 25 though still dying young. It is also recognised that intellectual age may not coincide with chronological age.

One established community service based in paediatrics has developed the following flexible policy in relation to age.

The Lifetime Service . . . provides care to children and young people with non-malignant life threatening conditions and their families. Our working definition of a life threatening condition is: *'Any condition, developed in childhood (0-19 years) that means the person is likely to die prematurely (before the age of 40 years)'*. This flexible and non-categorical approach to inclusion by the service was made very deliberately to try and prevent problems of exclusion due to disease group and age boundaries.

Mary Lewis, Senior Community Children's Nurse, The Lifetime Service, Avon Health District

2.3 Epidemiology

2.3.1 How many die?

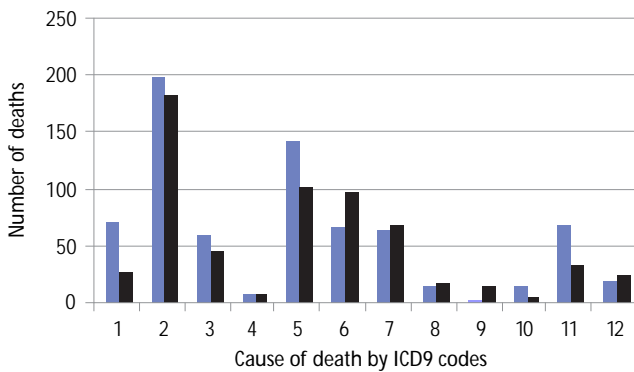
The maximum number of young people dying in 1998 who might have benefited from palliative care is as follows.

All groups	13 to 14	15 to 19	20 to 24	
England and Wales	1342	122	529	691
Scotland	143	12	66	65
Northern Ireland	57	6	26	25
United Kingdom	1542	140	621	781

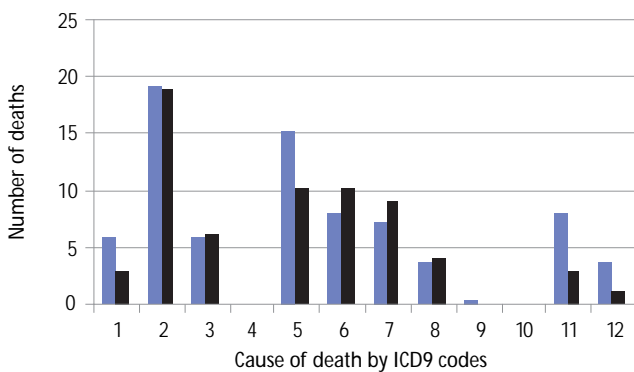
The estimated population for this age group is 7,705,720. This suggests that the annual mortality rate for young people aged 13 to 24 (inclusive) with life-limiting conditions is slightly over 1.7 per 10,000. Twenty-nine percent are due to neoplasms (ICD9 Gp. II).

The three graphs, for England and Wales, Scotland and Northern Ireland (page 11) summarise mortality in terms of cause of death. Data have been derived from Office for National Statistics (ONS) Series DH2, 25, Table 3 1998 for England and Wales; Table 6.4 1999 for Scotland; and Table 6.4 1998 for Northern Ireland. Please note that the vertical scales differ in the three graphs, because of the different population bases.

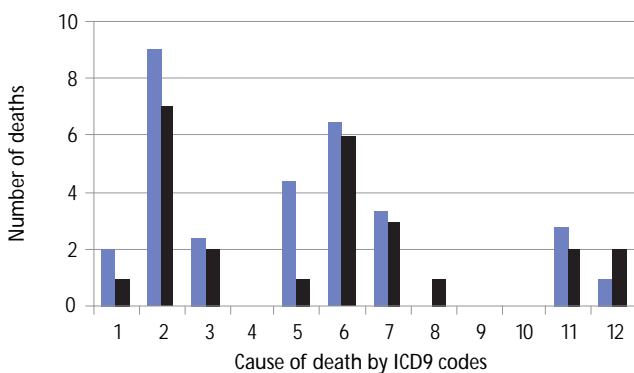
Mortality of young people (13-24) with life-limiting conditions, England and Wales, 1996. (Total number of young people who died = 1346)



Mortality of young people (13-24) with limiting conditions, Scotland, 1999. (Total number of young people who died = 143)



Mortality of young people (13-24) with life-limiting conditions, Northern Ireland 1998. (Total number of young people who died = 57)



Key

13-19yrs 20-24 yrs

1. ICD I Includes HIV infection
2. ICD II Includes cancers of digestive organs (mainly from age 20); bone skin and breast (from age 15); brain (mainly from age 20); lymphatic tissue (all groups); non-Hodgkins lymphoma (mainly from age 20); and leukaemia
3. ICD III Includes endocrine and metabolic diseases; diseases of endocrine and other glands; Diabetes mellitus (mainly in 20s); metabolic and immunity disorders; and cystic fibrosis (mainly from age 15).
4. ICD IV Diseases of blood and blood-forming organs.
5. ICD VI Includes hereditary and degenerative diseases of central nervous system; epilepsy; and muscular dystrophy.
6. ICD VII Includes ischaemic heart disease; diseases of pulmonary circulation; other forms of heart disease; cerebro-vascular disease.
7. ICD VIII Includes pneumonia; bronchopneumonia; and asthma.
8. ICD IX Diseases of the digestive system, including chronic liver disease.
9. ICD X Diseases of the genito-urinary system.
10. ICD XIII Diseases of the musculoskeletal system and connective tissue.
11. ICD XIV Includes congenital anomalies of the heart and circulatory system; & some Down's syndrome in their 20s
12. ICD XVI Symptoms, signs and ill-defined conditions.

2.3.2 How many have palliative care needs?

This question is difficult to answer, since such statistics are not routinely collected. It is clear that the prevalence is higher than the mortality data suggest, since many young people have needs over many years. Evidence from providers tends to come from the Children's Services and is limited to young people under the age of 19. Children's palliative care teams suggest that 13 to 19 year olds currently make up about one third of the caseload, but they feel that they are under-represented and in reality should form the majority of cases. We have made a rough estimate that there are between 6,000 and 10,000 young people in this category.

It is also clear that the patient population is inevitably growing since earlier diagnosis, improved feeding techniques (especially gastrostomies), clinical intervention and medication lead to greater survival into adulthood. In the last major publication on children from the Office of Population Censuses and Surveys (OPCS), in 1995, Botting and Crawley described this as a major emerging problem, likely to be associated with increases in morbidity (Botting 1995). The best data available for any chronic disorder are for cystic fibrosis. In this case, the improving survival means that more than one third of the CF population is over 16, the majority of severe morbidity occurs in early adulthood and the life expectancy of young people born in 1990 is in the region of 40 years (Anderson et al 1995). There are also data for young people with congenital heart disease, 70% of whom now reach adolescence and adulthood. Many have complicated conditions and need expert cardiological support (Somerville 1996).

Statistical evidence from children's hospices reveals that increasing numbers of their clients are now in their teens and that they make up between 26% and 54% of the total numbers, depending on the admission policy. However, it is not possible to base a national picture on these figures, since not all families use children's hospices and they are self-selected. There are no separate statistics for young adults from 18 to 25, though the Hospice Information Service in the current data collection (1999-2000) has introduced a new age group for 16-24 years.

2.4 Current legislation and guidance

2.4.1 Up to age 19

[Children Act 1989.](#)

[Children \(Scotland\) Act 1995.](#)

[Children \(Northern Ireland\) Order 1995.](#)

These provide the basic national policy on young people up to 19, including those with special needs. Support for young people and their families might include:

- Equipment and adaptations
- Help with housing
- Social work
- Counselling
- Interpreters
- Advocacy
- Short-term breaks
- Occupational therapy
- Benefits advice.

[Education \(Scotland\) Act 1980 \(including Regulations\).](#)

Governs the provision for special educational needs and the arrangements for recording in Scotland.

[Standards in Scotland's Schools Act 2000, Section 40.](#)

This establishes the duty of educational authorities to make arrangements for pupils who cannot attend school because of prolonged ill health.

[Education Act 1996 and Code of Practice on Special Educational Needs.](#)

[Education \(Northern Ireland\) Order 1996.](#)

These clarify that all children, when they are ill, have a legal right to education. They also say that children with a statement of special educational needs have the right to:

An annual review of educational needs and support from age 14 until they leave school. The name of a contact person for help and advice about any support needs. Help to draw up a plan for transition to adult services.

[Children's Service Plans](#)

Became mandatory in 1996 in England and Wales (amendment of Part 1, Schedule 2 of the Children Act), and in 1997 in Scotland (Section 19 of Children (Scotland) Act 1995). They provide a means of developing local strategy for young people bridging their needs between the range of authorities who provide services for the welfare of children and their families.

At the time of service transition

Education Act 1996 and Code of Practice on Special Educational Needs

This Act provides guidance on co-ordinated inter-agency planning for young people with statements of special educational needs.

"The first annual review after the young person's 14th birthday and any subsequent annual review until the child leaves school should include a Transition Plan which will draw together information from a range of individuals within and beyond the school in order to plan coherently for the young person's transition to adult life ... LEAs must seek information from Social Services departments as to whether a child is disabled and may require services from the local authority when leaving school. LEAs should also consult child health services and any other professionals such as educational psychologists, therapists or occupational psychologists who may have a useful contribution to make."

The Code of Practice has been monitored closely and a revised version is now in use, in which the responsibility has been devolved to schools.

This legislation does not govern young people without a statement of special educational needs.

Disabled Persons (Services and Representation) Act 1986 (Sections 5 and 6).

This says Local Authorities must assess the needs of disabled school leavers, taking account of carers' ability to continue the caring.

After 18

NHS and Community Care Act 1990.

NHS and Community Care (Scotland) Act 1990.
Health and Personal Services [Northern Ireland] Orders 1991 and 1994.

The local authority must offer an assessment if an individual might need services and invite other agencies (e.g. Health and housing).

The Chronically Sick and Disabled Persons Act 1970 (Section 2).

Chronically Sick and Disabled Persons (Scotland) Act 1992.

Chronically Sick and Disabled Persons (Northern Ireland) Act 1978.

In conjunction with the NHS and Community Care Acts, these Acts are important for independent living. They legislate on services such as:

- Practical assistance in the home
- Recreational facilities
- Help with travel
- Help with holidays
- Adaptations for the home
- Meals
- Telephones/ access to a phone.

Community Care (Direct Payments) Act 1996.

Under this Act, Social Services can give the money to pay for care services directly to the clients, who then make the arrangements themselves.

The Learning and Skills Act 2000

This Act promotes access to further education for students with learning difficulties or disabilities.

2.4.2 Recent Legislation

Legislation to watch, as it is introduced and develops:

[Care Standards Act 2000 in England and Wales and The Regulations of Care \(Scotland\) Bill in Scotland](#), which introduce new arrangements for the regulation and inspection of care homes and, for the first time, establish specific regulatory mechanisms for private and voluntary care providers.

[Human Rights Act 1998](#), which recognises and protects the freedom of the individual.

[The Carers and Disabled Children Act 2000](#) entitles carers to an assessment by the Local Authority. The Act allows direct payments to young people aged 16 and 17, and to carers, for the purchase of individual services. The Act includes provision of a Voucher Scheme to purchase respite care.

2.4.3 Guidance from the NHS

Children's services

"The welfare of children and young people in hospital" (DH 1991) (endorsed by Wales and Northern Ireland) and "At home in hospital. A guide to care of children and young people" (Scottish Office 1993)

These advise hospitals to accommodate adolescents in separate units from children's and adult wards, within children's departments. In this way, privacy, flexibility of regime and independence can be provided, as can appropriate recreational and socialising space. These reports also emphasise that nursing staff need appropriate training. For adolescents with life-threatening disorders, the reports emphasise the need for family-centred and flexible care, with community support services to help families to care for children in their homes. High quality respite care is described as a precondition for this type of care.

"Child health in the community: a guide to good practice" (DH 1996)

This endorses the principles for good quality care for young people, identified by ACT and published in their Charter (ACT

1995). It urges multi-disciplinary collaboration with Social Services and Education for assessment of a young person's needs. It encourages agencies to agree criteria for the identification of children in need and to co-operate in the maintenance of a register. It supports the appointments of named key workers and endorses the use of patient held health records.

"Evaluation of the Pilot Project Programme for Children with Life Threatening Illnesses" (NHSE 1998)

This was issued in the Good Practice series. It concentrates on managing a service, delivering a service and respite care, highlighting good practice.

Transition

"Our National Health: a plan for action, a plan for change" (Health Plan for Scotland) (Scottish Executive 2000)

This makes specific reference (in relation to "children who suffer from enduring illness") to the need for sensitive management of the transition from children's to adult services.

Adult services

To assist health authorities (and, in future, Primary Care Trusts) to plan and commission appropriate services, the NHS has issued a series of letters since 1994, which have progressively suggested a widening of the remit of palliative care services to encompass non-malignant diseases and to integrate the principles into wider practice. This guidance is not limited to any age group. However, the major emphasis is still on cancer services, which are part of a national health care priority initiative and, as such, must be included in Health Improvement Programmes.

Department of Health. Modernising Health and Social Services: national priorities guidance. 1999/00 – 2000/01.

This names palliative care as a priority. A palliative care strategy, based on the assessed health needs of the population, should guide services.

Calman/Hine Report A policy framework for commissioning cancer services (published under cover of EL(95)51).

Basic recommendations.

EL(96)85. A policy framework for commissioning cancer services: palliative care services

This amplifies EL(95)51, setting out the key principles underpinning palliative care. In addition to cancer, it names progressive non-malignant diseases that can have a palliative period (e.g. HIV/AIDS, multiple sclerosis).

HSC 1998/115. Palliative care

This encourages health authorities to integrate principles and practice of palliative care for all those facing life-threatening illnesses into the whole of NHS practice.

2.4.4 Information from other bodies

Other helpful discussions and recommendations are available from many sources, both statutory and voluntary and these are included in the References. Reports from the Audit Commission and the Joseph Rowntree Trust are often relevant. A particularly useful source is the House of Commons Health Select Committee, which looked at services for children and young people during the 1996-1997 session. Their third report, issued in 1997, has detailed information on needs, including evidence from parents.

2.5 Legal and ethical issues

2.5.1 General Points

Developmental issues in adolescence Any considerations about the ethics of care for young people under the age of eighteen must be tempered by two things: the fact that they are emerging as individuals despite the difficulties that illness may send their way, and that this personal development begins at a young age and varies in pace between individuals.

Development of the law This is an important area, not least because the law is developing at the moment (BMA 2000). Suffice it to say that the move is towards greater freedom and

autonomy for a young person during the transition into adulthood, which in turn affects the roles and responsibilities of staff and families over the journey of an illness.

Respecting the individual Treating and respecting everyone as individuals, recognising and protecting their freedoms, regardless of the age or intellectual capacity of the person, are core values of our society. This is now enshrined in the Human Rights Act 1998. How we apply these values is more difficult. In health care it is formalised as part of the clinician-patient relationship in three ways: the trust between the parties that discussion and advice will be truthful; the reassurance that the information is treated in strict confidence (unless it is thought that it could harm the patient or someone else); the duty of the clinician always to aim at promoting the patient's best interest. These principles apply across all those involved in discussion and decision making.

Capacity vs. the "age of majority" In England, Wales and Northern Ireland, once a person reaches 18, the age of majority, provided they have the capacity to think and decide independently, decisions around health care fall solely with them. Young persons between the ages of 16 and 18 may also have capacity to understand and judge for themselves (Family Law Reform Act 1969). Young people under the age of 16 have no statutory capacity, but can be "Gillick competent" because of the test laid down in the court case. (*Gillick v. West Norfolk and Wisbeach Health Authority*, 1985). For children, the threshold test is higher, in that the person under 16 has to demonstrate an understanding of the issues involved. Clinicians therefore have two tasks: to judge the capacity/competence of the young person; and then to involve the young person appropriately in decisions, ensuring his or her understanding. The decisions around health care then rest solely with the young person, but the clinician would be well advised to involve the parents whenever possible. In Scotland young people of 16 are presumed to be competent to make decisions about their medical care (see the Chapter on Scotland in BMA 2000).

Incapacity In the face of incapacity, clinicians or the courts are required to act in a young person's best interest. At the time of

writing, for young people over the age of 18 in England, Wales and Northern Ireland and over 16 in Scotland, no member of the family has the authority to make a decision, although they are entitled to express views. If, in the view of the clinician, a young person does not have the capacity to understand the consequences of the treatment, the clinician has the responsibility to consult the parents or whoever is in locus parentis before deciding on the best interests. Cases continue to go through the Courts and several are discussed by the British Medical Association (2000).²

The idea of "best interests" To act in the best interest of a young person includes evaluation of their overall wellbeing as well as the simple matter of whether an element of disease is likely to respond to treatment. Their view is therefore central to any decision about treatment. Whilst the views of family must be sought, and in general will reflect the interest of the young person, it is the interest of the young person and not the family that is primary and the courts support this. For further discussion of "best interests", see Chapter 1 in the British Medical Association's recent book on children and young people.

Confidentiality and disclosure Anyone, including a young person, is entitled to a relationship with their doctor which is confidential and truthful. All discussions should be open and honest. Whilst these should be sensitive and appropriate on difficult subjects, there is no defence for hiding behind capacity or age to excuse inadequate discussion, neither can family bar such discussion. Secondly, the clinician patient relationship is confidential unless permission is gained to disclose to others, including family, and this must be respected. In exceptional circumstances, where confidentiality is breached, clinicians must be able to defend their decision, as a young person would be entitled to take them to court.

²The BMA's recent advice is contained in "Consent, rights and choices in health care for children and young people". This book is a useful source of discussion on many of the issues raised in this Section

2.5.2 Consent & Refusal

Historically, there has been disparity between consenting and refusing, the argument being that a greater level of capacity is needed to refuse treatment on the basis that a clinician will only recommend what s/he sees is in the best interest of the patient. For example, in England, since 1990, several court judgements have over-ruled a young person's refusal of treatment opening a danger of generalisation from exceptional cases (Dimond 1996; Alderson 2000; BMA 2000).

However, The Law is becoming increasingly specific:

- The Family Law Reform Act 1969 (Section 8) states that people over 16 (in England and Wales) can give valid consent to treatment. It does not say that young people below that age cannot give consent.
- The Age of Majority Act 1969 allows 16 to 18 year olds to consent to medical treatment in Northern Ireland.
- "Gillick competence" relates to the young person's 'maturity and understanding and the nature [seriousness and complexity] of the consent which is requested... 'when [the child] achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.' and 'sufficient discretion to enable him or her to make a wise choice in his or her own interests.' (Gillick v. West Norfolk and Wisbeach Health Authority, 1985).
- The Age of Legal Capacity (Scotland) Act 1991, (Section 2) allows for young people under the age of 16, in Scotland, to give legally valid consent if their doctor considers that they are competent to make an informed and wise decision.
- The Children Act 1989, Children (Scotland) Act 1995, Children (Northern Ireland) Order 1995 state that children deemed to be competent can 'refuse medical or psychiatric examination'.

The General Medical Council and the British Medical Association have published recent books, providing clear guidelines on consent (GMC 1999; BMA 2000).

Advance statements (living wills) and resuscitation status

Based on the above, the need for consultation and discussion with a young person about decisions to resuscitate them, and the opportunity for them to formalise their views about future scenarios in an advanced statement should be no different from adults. Relevant documents, which include statements of the legal status, are:

- British Medical Association. 1995. Advance statements about medical treatment. London: BMA. This provides general guidance.
- Royal College of Paediatrics and Child Health. 1997. Withholding or withdrawing life saving treatment in children: a framework for practice. London: RCPCH.
- British Medical Association. 1999. Withholding and withdrawing life-prolonging medical treatment: guidance for decision making. London: BMA. This gives an extensive discussion of the ethics around care at the end of life.
- British Medical Association, The Resuscitation Council (UK) and the Royal College of Nursing. 2001. Decisions relating to cardiopulmonary resuscitation: a joint statement.
- UKCC. 1999. Guidelines for professional practice. London, UKCC.
- Contemporary guidelines on discussing resuscitation and other issues relating to patient care and the end of life can be found on the BMA website: [HYPERLINK http://www.bma.org.uk](http://www.bma.org.uk), under ethics.

"Passive" Refusal Sometimes patients refuse passively by defaulting from treatment. This may be a reflection of inadequate discussion in gaining consent in the first place or may be a way of asserting or establishing refusal when they feel unable actively to decline an intervention. It should be taken as a need for open and confidential discussion where a view can be gained without the influence of others.

Summary of 2

- Palliative care focuses on quality of life which, for this age group, is usually linked to the development of independence. The time scale for palliative care varies from many years to a few days. *[Section 2.1]*
- The spectrum of conditions involved is very wide. Some are congenital or genetic and are long term. Others are contracted in childhood, the teens or early twenties. *[Section 2.2.1]*
- There are two wide groups: those who are developmentally intact and those with severe neurological impairment. *[Section 2.2.1]*
- The age boundaries are problematic, since there is a continuum, with the needs of children evolving into the needs of young people, merging into the needs of young adults. *[Section 2.2.2]*
- The annual mortality rate for young people aged 13 to 24 with palliative care needs is 1.7 per 10,000. The maximum number of young people who died in the UK and who might have benefited from palliative care in 1996 was about 1,550. *[Section 2.3.1]*
- The prevalence of young people ill with palliative care needs is much higher than the mortality rate, though accurate data are not available. The patient population will inevitably grow since earlier diagnosis and improved techniques and management are leading to high rates of survival. We estimate that the number is between 6,000 and 10,000. *[Section 2.3.2]*
- The NHS issues guidance separately for children and adults. A series of circulars on palliative care has defined principles and widened the scope and time scale for adult services. *[Section 2.4.2]*
- The legal and ethical aspects, especially with regard to confidentiality, consent and refusal of treatment, are major issues for this age group. *[Section 2.5]*

3. The different needs of young people

3.1 Crises in late adolescence and early adulthood

This age group has a higher proportion of those needing palliative care than do younger children or "young adults" - a term used by the Office for National Statistics (ONS) for those under the age of 65. There are several possible reasons for this high proportion:

- Many chronic progressive conditions reach a crisis during adolescence and young adulthood, in terms of physical deterioration. Many young people with these disorders die in their late teens or twenties.
- Improved therapy, which is not curative, currently delays onset of symptoms from childhood to adolescent years.
- Prevalence of diseases such as HIV and AIDS will lead to a growing number of young adults with specific palliative care needs in the future.

3.2 Developmental issues in adolescence

Work with this age group demands detailed understanding of the continuing rapid development in physical, emotional, social and cognitive spheres. Such development continues in all or some of these areas, despite the onset of acute illness or impairment due to progressive deterioration. Hence it is important to consider the reactions and needs of young people with a life-threatening illness in the context of normal adolescence. In the past 50 years, our understanding of the sociology, social, developmental and educational psychology of young people has crystallised and there are good descriptions of the 'developmental tasks' that young people have to meet (Stevens 1998).

Summary of developmental tasks of adolescence

Forming a clear identity

Accepting a new body image

Gaining freedom from parents

Developing a personal value system

Achieving financial and social independence

Developing relationships with members of both sexes

Developing cognitive skills and the ability to think abstractly

Developing the ability to control one's behaviour according to socially acceptable norms

Taking responsibility for one's own behaviour

(Based on Havighurst 1952, reported in Russell-Johnson 2000)

Several studies divide this transitional period into three phases, early, middle and late. Although this is rather arbitrary and with blurred boundaries, it can help in the understanding of behaviour, relationships and impact of the illness. The following table is derived from the work of Stevens and Dunsmore (1996).

Age	Early adolescence 12-14 years (female) 13-15 years (male)	Middle adolescence 14-16 years	Late adolescence 17-24 years
Key issues and characteristics	<ul style="list-style-type: none"> Focus on development of body Most pubertal changes occur Rapid physical growth Acceptance by peers Idealism Mood swings, contrariness, temper tantrums Day dreaming 	<ul style="list-style-type: none"> Sexual awakening Emancipation from parents and authority figures Discovery of limitations by testing limitations, boundaries Role of peer group increases 	<ul style="list-style-type: none"> Defining and understanding functional roles in life in terms of: Careers Relationships Lifestyles
Social/relationships, behaviour	<ul style="list-style-type: none"> Improved skills in abstract thought Foreseeing of consequences, planning for future Physical mobility prominent Energy levels high Appetite increased Social interaction in groups Membership of peer group very important 	<ul style="list-style-type: none"> Relationships very narcissistic Risk-taking behaviour increases Intense peer interaction Most vulnerable to psychological problems 	<ul style="list-style-type: none"> Increasing financial independence Planning for the future Establishment of permanent relationships Increasing time away from family
Impact of life-threatening illness	<ul style="list-style-type: none"> Concerns about physical appearance and mobility Privacy all-important Possible interference with normal cognitive development and learning (school absence, medication, pain, depression, fatigue) Comparison with peers hindered, making self-assessment of normality more difficult Possible lack of acceptance by peers Reliance on parents and other authorities in decision-making Hospitals perceived as very disturbing 	<ul style="list-style-type: none"> Illness particularly threatening and least well tolerated at this stage Compromised sense of autonomy Emancipation from parents and authority figures impeded Interference with attraction of partner Fear of rejection by peers Limited interaction with peers may lead to social withdrawal Dependence on family for companionship and social support. Hospitalisation, school absences interfere with social relationships and acquisition of social skills Non-compliance with treatment 	<ul style="list-style-type: none"> Absences from work, study Interference with plans for vocation and relationship Difficulties in securing employment and promotion at work Unemployment hinders achieving separation from family and financial independence Discrimination in employment, health cover and life insurance Loss of financial independence and self-esteem Concerns about fertility and health of offspring

3.3 Complexity of management

There are complex interactions between physical health and mental well-being and also between the individual and the surrounding system. The psychological needs of this age group are very complex. Young people may be intent on completing the 'developmental tasks' (see Section 3.2) while socially isolated due to their disorder and increasingly dependent for some aspects of daily living. At the same time they need to make psychological adjustments to their illness and impending death.

The management of some of these young people necessitates complicated dietary regimens as well as pharmacological agents. Physiological changes may be reflected in a changing need for medication and often body weight needs to be considered, a practice that is more common in paediatrics than in adult medicine.

There is usually a continuing need for physiotherapy and occupational therapy and sometimes speech and language therapy too. Occupational therapy is very relevant, since its main focus is meaningful occupation and its emphasis is on quality of life. Occupational therapists provide assessment and intervention relating to functional skills at home and in school/college. These include motor and perceptual skills and cover activities ranging from eating and dressing to handwriting and use of information technology.

3.4 Survival into adulthood and lack of services

As far as adult medicine is concerned, a proportion of this cohort forms a largely 'new' group, for which no services have previously been provided. Many of the disorders were formerly limited to childhood and good services have been developed by children's departments, in hospital and particularly in the community. These services are generally complex and multi-disciplinary. As these young people approach adulthood, it is not clear to paediatricians which adult clinician would be most appropriate to hand them on to. Up to now there has been little call for adult physicians to develop expertise in these areas. In the same way,

multi-disciplinary paediatric community teams find that similar co-ordinated services rarely exist in the adult sector and they struggle to locate a group of people to take over their work. Many young people report feeling 'cast adrift'.

In particular, there is an extreme scarcity of adequate respite services, which can provide the complex management required. Young people with disabilities and those with progressively deteriorating conditions place a huge demand on their parents, who are often middle-aged and are ill-prepared, emotionally, to take on the nursing care of a young adult.

Summary of 3

- This group of young people needs special consideration since it is growing in size as children with life-threatening conditions survive longer. Many chronic progressive conditions reach a crisis during late adolescence and young adulthood. *[Section 3.1]*
- Many of the disorders were formerly limited to childhood, so that no services have been developed in the adult sector. *[Section 3.4]*
- Work with this age group demands detailed understanding of the rapid development in physical, emotional, social and cognitive spheres, which continues despite the onset of acute illness or progressive impairment. *[Section 3.2]*
- Management is complex because of the interactions between physical health and mental well-being and between the individual and the surrounding system. *[Section 3.3]*

4. Key issues raised by young people

This section is firmly based on the views of our Young Persons' Forum and the headings are indicative of the subjects the members felt were important. In addition there are quotations taken from the written submissions and the literature. Of the published literature that focuses on the views of young people, much is based on cancer, which is only one of the life threatening disorders. However, we believe that the examples we have chosen have a general applicability.

4.1 Involvement in decision-making – health issues

"At one point I decided not to take my calcium tablets – they tasted like chalk. But then the doctor explained the pros and cons and I realised that they were right. I could then evaluate the situation and make a decision. Sometimes this information stage is missed out."

"It is very important to me that I have all the information available – not the softer option that people think I need, but the straight truthful knowledge and information that they know. I need all the information to make choices, choices that affect me. I don't want to feel people are keeping things from me."

"I took over decision making very early. I'm responsible for my own condition. It's my own choice."

Notes from the evidence

Independence often starts with a young person taking over the responsibility for their treatment and much evidence revolved around this issue. Involvement is based on communication and this includes information giving, listening, discussion and negotiation. If the options are understood, a young person's personal preference about what is going to happen to him or her on a whole spectrum of issues from choice of daily activity to decision on when to stop treatment can be pivotal in the planning of the care package. With good information and support, and if they are well enough, some young people can take over the organisation of their own lives.

However, young people with a long-term life-threatening disorder have often been brought up in a very protected environment. Some have rarely been involved in decision making about their own care and are essentially dependent on their parents or carers for all activities of daily living as well as consent for clinical and other interventions. Even when the young person is cognitively aware, parents may find it difficult to accept that their child is old enough to make decisions for themselves.

Not all parents believe that their children should be informed of their diagnosis and prognosis. A very common conflict for staff is when a young person under the age of 16 requests information which their parents have asked to be kept from them. The expression of individual and differing viewpoints by the young person, family members and professionals can also cause conflict, especially when it involves consent to treatment or when to stop further treatment

These issues are discussed further and some solutions described in Section 5.7.

4.2 Attention to psychological needs

"I didn't want to talk about it. I wanted to handle it on my own. But that faded so quickly, because you are so helpless. You really do need somebody that can come in and help you." (Sourkes 1982)

"Vanity is a strong word, but you worry about your physical appearance, how it's going to look, how people are going to react. You lose all self pride and self-respect" (Sourkes 1982)

"Friends don't know how to react... They don't know what you are going through. So mostly you are alone." (Sourkes 1982)

"You see friends who are sick; and friends die. Then you lose a support network as well as a friend."

"Sometimes I feel exceptionally guilty when I catch an infection and get very low. I need someone to talk to about both medical things and emotions."

Notes from the evidence

Young people with life-threatening disorders have tremendous psychological issues to come to terms with. Unlike children, they often fully understand their disease, its prognosis and its effects on self and family. However, like adults, they do not always have defence mechanisms to cope with the anxiety and uncertainty of the illness and its implications (Evans 1993). At a time when peer group support and acceptance are particularly important, young people with life-threatening illness find themselves separated from their peers and with a heightened orientation to and dependence on adults. Their self esteem is frequently low and aspirations poor. Sometimes they are struggling with concerns about body image. They can see themselves out of control and their responses may include denial, withdrawal and anger. These make communication difficult, at a time when parents tend to become over-protective, so that conflict can arise.

Psychological support is particularly important at the time of transition to adult services, when a young person can feel very insecure or even 'cut adrift' – they may link adult services with their inevitable death and need a lot of reassurance. Some young people who may be developmentally below their chronological age, may be emotionally unable to cope with such a move without a great deal of support.

These issues are discussed further and some solutions described in Section 5.4.

4.3 The process of transition from children's to adult health services

"You start at base-line again when you go to adult services."

"They have a great file of notes, but they don't know you."

"I felt as if I was cast adrift and became a problem because I had lived longer than anyone thought and now there was no real provision at a time when I would possibly start to hit problems with my metabolic condition."

Notes from the evidence

Much evidence was received on the transition process, including some powerful comments from parents:

"Everything stops at 18. Everything is a battle."

"The young person doesn't change. Services do."

"She wasn't meant to be 18. No-one knows what to do with her."

The evidence is analysed separately and some suggestions offered in Chapter 6.

4.4 The inexperience of adult health services

"I feel I should be regarded as a person with a metabolic illness and my main consultant should be a doctor who has a good knowledge of that condition. Then there should be a renal specialist for the kidney side and the two should liaise with each other."

"I should like to attend clinics set up specifically for my condition, even if it means travelling."

"The staff tend to panic when faced with a patient with a rare condition and impose greater restrictions. They are scared because they don't know enough about it."

"I caught shingles and became really ill. The paediatrician I had been under since the age of seven, who had so much experience of my condition, was not told or contacted on site at the hospital. Eventually they rung a doctor who has a lot of knowledge of cystinosis and who practises in London."

"Physio petered out. I had it twice a week as a child."

Notes from the evidence

A consultant cardiologist summarises the issue for her own speciality, but her words could be echoed for many of the conditions we are considering:

"Grown-up patients with congenital heart disease are the costly fruits of our labours, and they deserve continued expert medical care as adults." (Somerville 1996)

For young people with complex needs over the age of 18, there is no one person designated to take on the overview role of the community paediatrician, ensuring that all the specialists are pulling together on behalf of the patient. Hence care can become fragmented.

While in full-time education and under the care of a paediatrician, young people with special needs are provided with physiotherapy, occupational therapy and speech and language therapy as appropriate, by several agencies in many locations, often as part of a comprehensive paediatric team. In both treatment and prevention, these services have proved very effective. However, in adult services these therapies are much rarer, except perhaps in learning disability teams. There is usually no equivalent team for young people with physical illness or physical disability to transfer to.

These issues are discussed further and some solutions described in Sections 5.1, 5.2. and 5.6.

4.5 Concerns about parents and siblings

"My best friend died and I kept in touch with her parents and they were so devastated. I feel so guilty about my parents. I must try to keep well so that I don't upset them."

"... I didn't know how to comfort them. I was going to tell them it would be alright when I didn't know myself." (Sourkes 1982)

"Sometimes parents need help. Sometimes they need looking after. Then I would like to talk to someone else. I wouldn't want to upset them."

"You can ask for your family's support, wisdom, experience; but it's not fair to burden them. I have an older sister whom I talk to, but at the same time, I don't want to upset her. I don't want to make her cry for me." (Sourkes 1982)

Notes from the evidence

It is reported that young people and their families often try to protect each other from painful information (Thompson 1990; Bluebond-Langner 1996). A correlation between poor coping in the family and over-protection of the sick child has also been noted (Birenbaum 1990).

Often sibling relationships are strong, and a sibling can become a major confidante of the sick child. However, when the siblings themselves are adolescent, their problems are complex. Often they worry about their parents' coping abilities. At the same time they need to pursue their own lives while anxious about their sibling. At a time when they need stability, the family is destabilised (Whyte & Smith 1997).

These issues are discussed further and some solutions described in Section 5.9.

4.6 Ambivalence about parents' role

"Friends don't know how to react. So mostly you're alone, and I think you depend very heavily on family."

"When I was in hospital, I would have valued my Mum being there as I constantly had to explain many different things. This took a lot out of me whilst feeling so ill."

"There were times when my doctors would come in and ask: 'How are you doing?' My mother would answer. I wanted to tell them how I felt."

"Later, I didn't need my mother so much. But I didn't know how to tell her, because she needed to feel needed, and to think that I depended on her." (Sourkes 1982)

"Younger children... can still be with their mother. Older people are away from their mother; they're detached, more adult. When you're in the middle, parents don't want to let you go. You want to be set free a little bit, but you want to be able to come back." (Sourkes 1982)

In connection with a proposed teenage unit at a hospice:

"It's great to be able to get away from my parents."

Notes from the evidence

It is widely reported that, despite adolescent efforts for independence that can cause some turmoil in family life, young people with a terminal illness still have a great need for their parents, especially when hospitalised. Hence Viner and Keane (1998) propose unrestricted visiting for parents and ample accommodation for overnight stays. When living independently or even with a partner, the evidence from our Young People's Forum suggests young people still tend to return home when they become ill. However, young people living at home and cared for by parents, usually welcome the opportunity for respite away from the family. Some young men, for example those with muscular dystrophy who are cared for by their mothers, may have very little male company and welcome the opportunity to get away and meet their peers.

In the later stages of their illness, young people often draw very close to family members.

4.7 Desire for independent living

"I am aware that I can never really be independent because I have special needs and cannot get a job. But it's difficult. I don't want to sit at home and watch telly and I can't go on the buses by myself."

"Grandparents can be very over-protective. They still think that I am very little. And my mother likes to keep an eye on me! Parents can worry too much and make it difficult. But you still need their support"

"Moving away from home is scary, especially the first night. I had never really been away before."

"I really need 24 hour support, but I live independently and I'm in control of my own care package. I'm in charge of hiring my own assistance. I advertise in TNT magazine or locally. I always interview. When I first left home, I was at college in a different county and the local authority had to arrange to transfer money for a care package. Funding can be a problem."

Notes from the evidence

There is a strong feeling in the evidence that over-protection can make a young person more disabled. Parents often need assistance in allowing their children the independence they are seeking. Support should be available to help young people maximise their potential for independence, especially through the provision of opportunities to make choices. Many could do with an independent advocate, someone who is separate from the family and health carers. A small number of this group of young people with life-threatening conditions aspires to independent living. More are going to college or university and then hope for an independent career. Those in wheelchairs who need 24-hour support can attain a degree of independence and it is likely that this group will increase in the coming years. The expectation of what is possible must be introduced early enough. The potential of a young person is built up over a number of years, in particular when their expectations are high

Many young people are dependent on others for all aspects of care and often this is female oriented, so that young men have a dearth of male company. Opportunities for peer companionship as well as privacy and choice are limited. To maximise social and leisure opportunities, and to increase flexibility, young people would like carers of a similar age who could appreciate the difficulties and enjoy going out.

There is disquiet expressed in the evidence about the provision, renewal and maintenance of equipment and aids. To ensure a degree of independence and some privacy for a young person, especially those in wheelchairs, planning for equipment and house modifications should start well ahead. Apparently, commissioners are funding too few occupational therapy posts and there is also a shortage of money for equipment. For adult services, there is also a shortage of occupational therapists.

For all these reasons, access to supportive advice is limited and hence the likelihood of independence is reduced.

These issues are discussed further and some solutions described in Section 5.12.

4.8 Importance of school, college and employment

"I never indicated that I wanted special favours. I just wanted to be treated normally." (Sourkes 1982)

"It's important to make friends, but teachers can hinder this. I had to be careful what I ate. I couldn't eat school meals, but the headmistress did not want me coming in with my packed lunch. I had to eat my dinner by myself in the sick bay every day."

"The independent living adviser advised me that it would be difficult for me to find a job. And he was right though I didn't want to hear him. He was actually wise and was warning me about the problems. I tried working, but have now given up my job and am doing voluntary work."

Notes from evidence

Young people often feel an increased need to preserve normality (e.g. school attendance) even if this seems foolish to adults. Disrupted schooling and education can be a particular source of anxiety. Some young people set themselves very high goals and strive to excel at school or college, despite considerable difficulties. Some will need careers advice, vocational training, or assistance in moving away from home to university.

Even if the young person is becoming cognitively impaired, teachers work hard to offer appropriate educational goals. In this way educational aspirations can be met and students' expectations of themselves can be maintained.

For young people moving into further education, legislation on co-ordinated inter-agency planning does exist (Section 2.4), but resource shortfalls mean that comprehensive, multi-disciplinary input is rarely available. Links between

occupational therapists and the Connexions Service (dealing with further education and training needs) should also be established.

4.9 Opportunities to do things that other young people do

"I need my own space and independence. I am still a teenager. I don't want to be smothered and over-protected. I value my independence and privacy. I need private space to relax and be me."

In connection with a proposed teenage unit at a hospice:

"Great idea. It will be great to be able to stay with people my own age, and to have a chance to talk over common problems. It will be nice to have our own space."

and

"If this unit goes ahead, it would mean we shall be able to do what every teenager wants to do."

"PE is dreadful in my school. We had an experience with badminton. Everyone else played over the nets, but we did it between the courts. We didn't have any training or anything."

"You still want the chance to have 'normal' friends who have never experienced being sick. You don't want to be denied those friends..."

"Firstly I would like not to be pressured, not to be constantly 'got at' and reminded of my condition. I would like everyone to treat me as a teenager first and my condition last."

"My mum said 'You're not like everybody else. So be careful. But I think you have to decide for yourself and go out there and try it."

"I was sat down by my paediatric consultant who said 'It might seem that people with your condition have a low fertility rate. But don't rely on it. So that was the sex bit. I was not quite expecting it. I think there was also the feeling that you might, perhaps, go out and have a knees-up because you are not expecting to be around much longer."

Notes from the evidence

This age group is particularly responsive to the influence of their peers and the opportunity to chat with their friends and do ordinary teenage things is important to their development. Many young people with life threatening disorders can become isolated, so that such an opportunity is no longer an everyday occurrence. It is not always easy to arrange activities that satisfy, as is indicated in this message from the mother of a 15 year old girl with Ataxia Telangiectasia (J):

"J. only has contact with people at school. Friends don't call in the evening to invite her out. She stays at home at weekends. She and I have agreed that if a scheme is available, she will do it, if only to increase contact with people. So she does Riding for the Disabled. But she wants to be 15 and talk about 15 year-old things. It's not the same doing things with your Mum!"

This example is typical of disorders that are beginning to cause problems of balance, speech or co-ordination. An illness like cancer can also engender social and emotional isolation. Links with peers are lost due to a variety of causes, such as: friends overwhelmed by illness and unsure how to offer help; friends moving on and getting a boyfriend/girlfriend; missing time at school or college; diagnosis interrupting transition between school and work; having to miss a year at school; feeling different, part of a world of illness, treatment and death; and loss of confidence. In this respect, students in a school for the physically disabled may find it easier to maintain interactions with their peer group than those attending mainstream schools.

These issues are discussed further and some solutions described in Section 5.10.

Summary of 4

From the Young Persons' Forum:

- The importance of being viewed as a young person first and as being unwell as a secondary consideration. *[Section 4.9]*
- The need for involvement in decision-making on health issues. *[Section 4.1]*
- Attention to psychological needs and emotional support. *[Section 4.2]*
- The process of transition from children's to adult health services. *[Section 4.3]*
- The inexperience of adult health services with many of these conditions. *[Section 4.4]*
- Concerns about their parents and siblings. *[Section 4.5]*
- At the same time, an ambivalence about the parents' role. *[Section 4.6]*
- The desire for independent living. *[Section 4.7]*
- The importance of school, college and employment. *[Section 4.8]*
- Opportunities to do things that other young people do, including sexual experiences. *[Section 4.9]*

5. Unmet needs and some solutions

5.1 Appropriate community services

Due to the relatively small numbers of young people with certain of these conditions surviving to adulthood, services designed specifically for them have not been developed. They are unlikely to occur, unless all the young people who are in need of a similar service are designated as one group. This is what has happened in the case of the Lifetime Service in Avon Health District, described below.

The Lifetime Service

This community support is provided for people with non-malignant life-threatening childhood conditions, who are likely to die before they are 40. It is provided by a team of community children's nurses and clinical psychologists, and supported by paediatricians and local social service departments. It is clear from our research that the transition to adult care for these people by all agencies is a particularly difficult time and we want to be able to facilitate this process rather than contribute to the problem. Families welcome this inclusive approach and we are able to remain involved with them as long as a paediatrician remains involved in their care, if this is what they want. However, other services with which Lifetime works have different criteria. We are unique in not having to cut off at the age of 16, 18 or 19 years. But this means we stand alone and suddenly run out of resources that can be tapped into.

Mary Lewis, Senior Community Children's Nurse,
The Lifetime Service, Avon Health District

There is some evidence, reported in the literature (Chamberlain and Guthrie 1996), of the success of multi-disciplinary teams set up under the auspices of rehabilitation services, to serve the needs of young people with disabilities. These teams are limited in number, exploratory in nature and are aimed at young people with static conditions. Their aim is to empower young people to organise for themselves appropriate systems of clinical and social support, but they might prove a useful model for young people with progressive conditions. The establishment of such multi-agency teams would be of real value to young people with

life-threatening disorders. Legislation already provides guidance for different agencies to work together (Section 2.4).

The Leeds Rehabilitation Service

The Leeds team relates to a consultant in rehabilitation medicine and consists of a doctor, physiotherapist, occupational therapist, speech therapist, social worker and psychologist. Regular contact is kept with professionals in further education and employment. Particular attention is paid to effective working between all agencies and to the co-ordination of interventions. Work continues over several years – a single transition plan at school leaving has been found to be inadequate. The team's functions include:

- Helping access to the best medical care for the impairments related to the specific diagnosis
- Imparting skills of health maintenance
- Imparting life skills, particularly relating to further education, training, work, relationships and the productive use of leisure.

An evaluation (Baines and Chamberlain 1994) showed that, as a result of the team's work, suitable equipment was provided promptly and many medical, social and educational contacts were effected in a short time.

Information from Chamberlain and Guthrie, 1996

Every adult has access to a district nurse who may be well placed to provide on-going care in the community.

5.2 Co-ordination of Care

Adult services are less holistic and less co-ordinated than children's services. When interventions are required from several clinicians, there is no one person to take an overview, a role that in childhood is carried out by a general or community paediatrician. This could be a natural role for the GP, especially the monitoring of various medical inputs. This should perhaps

not be confused with a key worker's role, which evidence suggests GPs do not have time to offer.

The key worker should know the young person well, be totally conversant with all the agencies and organisations that might help to meet his/her needs (including education and work), and act as an advocate/support for the young person. The key worker may come from one of several professions in the multi-disciplinary team and, of course, the young person must be involved in the choice. As a young person grows up and his/her needs change, it may be necessary to change the key worker.

Who should be the named key worker? – an example from Duchenne muscular dystrophy

"I fervently believe that a key worker should be somebody who has specialist knowledge and training and who knows how other agencies operate, in order that they can access the services needed. Too often it is left to somebody who does not have either the knowledge or the time to do this properly and families spend their time explaining time and time again to various personnel what their needs actually are. In many cases the families themselves don't actually know what their needs are and it really takes somebody with specialist knowledge to be able to help them understand where in the continuum they are. I feel this is particularly important in the terminal stages as families feel more confident with somebody who knows the condition inside out."

Veronica Watters, Family Care Officer – MD Campaign

5.3 Respite care

Adequate provision of respite care is essential to minimise the effects of illness/disability and improve quality of life. Yet for young people over the age of 18, there is very little suitable respite provision, whether it is a local short break, in the home or a longer period away from home.

Difficulties in providing suitable and accessible facilities have been researched and described on behalf of the Rowntree Foundation (Prewett 1999; Servian et al 2000). This group of young people is very vulnerable and yet they are often moved into environments where they are side by side with adults with learning difficulties and mental health problems. This is not in their best interest; and appropriate respite provision is a major gap in services. This is particularly significant when the young person's cognitive age is below that of an adult, where perhaps a child-oriented environment would be more acceptable to the family. Most young people are still cared for by their parents in the family home. The parents are becoming middle aged and are often exhausted by lack of sleep and the pressure of obtaining equipment and other aids.

Many adult hospices / palliative care services say that they are willing to accept young people. A few have accepted and satisfactorily managed a small number of young people (1 or 2 per year), mainly in the terminal stages. But they have experienced problems with more active young people attending for respite (e.g. young men with muscular dystrophy), especially in relation to independence, personal care and embarrassment, issues around sexuality and social activities. Perhaps the model established at Rachel House (see Box in Section 5.10) could be developed, so that respite centres set aside several weekends a year for young people to get together.

The best practice described to us comes from the children's hospice sector. Several have felt impelled to make their own arrangements for young people, on finding no appropriate service to hand them on to. Acorns Hospice in the West Midlands has opened a special unit at Walsall for young people. Douglas House in Oxford is planned to open in 2001. (see box below). Phoenix Lodge in Milton Keynes is in an advanced planning stage.

The philosophy of Phoenix Lodge, a hospice and respite care centre for young people with life-threatening conditions and special needs

Phoenix Lodge will provide an environment where young people can have space and freedom, noise and peace, opportunities to enjoy themselves, fulfil ambitions, try out new ideas and share friendships within a framework of care and support.

Living with a life-limiting condition can be frightening. Caring for someone with a life-limiting condition can be isolating. Being the relative, friend, teacher, colleague or neighbour of someone with a life-threatening condition can make you feel inadequate. Phoenix Lodge will act as a community, providing help, time and understanding to those people involved in the wider network of support for the young people, both whilst at Phoenix Lodge and once back home.

From the Operational Policy, Phoenix Lodge

Firm plans for a respite for young adults: Douglas House
 "Douglas House will be for young people between the ages of 16 and 40 and will offer outreach services, day care, respite care (with the provision of 6 or 7 beds), terminal care and bereavement support. We will respect young people's desire to be as independent as possible and will be sensitive to the fact that while parents may still have a practical as well as emotional involvement, partners may have taken on a vital role. We plan to provide recreational facilities and up-to-date IT equipment to enable study and ease communication. We envisage... it may be used by young adults with genetic conditions and congenital heart disorders as well as such illnesses as motor neurone disease and HIV related illnesses."

Sister Frances Dominica, Founder and Director of Helen House and Douglas House

Several hospices now run both adult and children's services and they may be able to solve some of the problems and come up with a model that might be more widely applicable. For example, now that the Pasque Hospice has opened Keech Cottage for children, there are plans to open a bed that will be linked between the two hospices for young people's use. Appropriate documentation is being developed to assess the needs of this age group. The decision will then be made as to whether they will be nursed by the adult team or the children's team, taking into account the young person's and the family's wishes. Whichever setting is chosen, at least one member of staff should have undertaken specific education and have experience in the care of young people.

Other young people use nursing homes for respite care. For example Sue Ryder Care runs care homes providing respite care for one or two weeks. They aim to cater for patients with a wide variety of conditions and to provide a personal and individual service.

5.4 Psychological care

All who provided evidence, from the young people themselves to the professionals looking after them, agreed that psychological care was an important aspect of care. The evidence suggested that all professionals should be able to offer emotional support, and training should be provided. Most young people are capable of discussing their prognosis, but they need to set the pace of such discussions (Carr-Gregg et al 1997). At such times, a 'neutral' professional may be able to provide the necessary support and help the young person to get to the root of their feelings (Sourkes 1982). Currently there is considerable inequity in access to psychosocial support, both between specialities and also between children's and adult services.

Because of the complex emotional demands of this age group, the support of a clinical psychologist should be available as and when needed, without long waits. Clinical psychologists should be core members of caring teams, offering interventions to young people when needed and also working with groups, as in the illustration below. They should also offer support to staff, parents and siblings.

Issues that may be addressed by clinical psychologists might include:

- Understanding and adjustment to functional disability arising from the condition
- Managing feelings, for example anger
- Adherence to treatments
- Body image and identity issues
- Expressing loss
- Preparation for transition to adult services
- Pain and symptom management
- Help with making decisions about possessions after death
- Funeral planning
- Referral for spiritual help

There is a growing body of evidence from hospices (see boxes in Sections 5.3 and 5.10), from residential homes (Section 5.14) and from the voluntary sector (Tak Tent in Section 5.10 and Teen Spirit in the box below) that the very act of bringing young people together is in itself a support and an aid to care and treatment. The Teenage Cancer Trust (2001) has just published a study based on its ten years experience of providing specialist facilities for teenagers, in which it identifies the culture of the unit itself as the pivotal source of support.

A seminar arranged by Teen Spirit

Teen Spirit is the only service in the United Kingdom specifically for teenagers who know that they are HIV positive or who live with a family member who has the virus. The aim of the group is to provide an informal environment in which young people can feel free to share their concerns and feelings without fear of condemnation. The seminar drew on the paradox of wanting honesty within the family but feeling the need to be secretive in the outside world. Fear of discrimination if the truth were known was a great concern of all the teenagers. Some pretended that their parents were suffering from cancer because this is a socially acceptable disease. Those who were HIV positive themselves had found it very hard to lead a normal life at school and college, trying to avoid explaining to friends why they had to take regular medication or why they were so often ill.

Reproduced from *Cascade*, 35, June 2000,
with permission from Action for Sick Children

5.5 Shortage of therapists

Services such as physiotherapy often reduce dramatically when young people are transferred to adult services, though it seems unlikely that their needs have changed. Thomas et al (1989), in their study of 104 severely disabled young adults, found that only 28% were receiving regular physiotherapy after leaving school. Therapists based in Social Services or colleges may dispute responsibility, for example for maintenance or upgrading of equipment. All other therapy is only available by general practitioner or consultant referral, usually to the local hospital.

There is a national shortage of occupational therapists and hence a shortfall in advice for house adaptations, equipment to improve quality of life and support for independent living.

5.6 Terminal care

For terminal care at home, there can be a gap in expertise, especially for young adults, causing reluctance amongst service providers to take on the home care of this group. General practitioners and their team should be involved, but may lack experience and support. Paediatric nurses will sometimes lack confidence in the symptom management of older patients. Adult community and Macmillan nurses may have similar concerns when faced with a young adult, especially when the patient is dying from a non-malignant disorder. Wherever possible the family, together with their GP, should be allowed to choose who should take on the key co-ordination role.

Most practical research in this field comes from Oncology, as is shown in these two examples from clinical nurse specialists. Choosing what is best for each individual is the ideal, but the ongoing issues of funding children's services versus adult services has not been addressed.

Flexibility for terminal care – an example from Oncology

The specialist paediatric nurses at the Royal Marsden NHS Trust have been instrumental in developing close working relationships with their adult palliative care colleagues, to manage complex symptoms and address the specific needs of young people in advanced and terminal stages of their illness. They have found much to learn from each other, especially about attitudes and ownership of care.

In understanding the developmental stage, they found that neither 'owns' the patient – they are not in an extension of childhood or a part of adulthood. They are unique.

Family-centred care, central in paediatric practice, is not at the forefront of the minds of adult nurses. The patient comes first and then the family, if there is time. Both sides needed to bend a little.

Who is the best to look after each young person? Look at each case individually and then decide who is most appropriate.

Choice of care environment for young people and their families is of utmost importance, whether this is at home, hospital or in a hospice. This should be addressed at an earlier stage of their progressive illness, particularly when facing challenges of transition of care for these patients.

The result is a flexible system that enables young people to move between services and professionals. However, they do not feel that an ideal service is possible yet. It needs a step-by-step approach. One thing that they have learned is that they should give the same message: the needs of young people are different.

Based on evidence from Nina Patel and Jackie Edwards, Clinical Nurse Specialists, Paediatric Oncology Outreach Nursing Team, Royal Marsden NHS Trust

Bringing together a network of support for the adolescent in the community – an example from Oncology

In looking to improve our services, I think that it is critical that there is a clearly identified professional who will lead services for this patient group. An identified professional can work to bring together a network of support for an individual patient, as well as developing a more structured service within a centre. In Leeds this has been through the development of a post of Clinical Nurse Specialist in Adolescent Oncology, with the support of Macmillan. This nurse is dedicated to identifying the needs of each young person and working with them and as an advocate for them, in addressing those needs.

Rachel Hollis, Chair, Paediatric Oncology Nurses Forum, Royal College of Nursing

Hospice care may sometimes be considered, especially when there are difficult issues of symptom management. But it is often difficult to find an appropriate environment for a young person, who may seem too old for a children's hospice and too young for the adult service. This may lead to their staying in the acute hospital setting, which generally is not ideal for this age group or for terminal care. Ethnic minority groups need particular consideration, as they are less likely to turn to institutional care.

If terminal care is needed at the time of the transition process, there are additional problems for both the caring team and the family that need to be solved.

5.7 Involvement in decision-making

Negotiation and explanation of the issues is essential, even though it might be time-consuming, to help the young person (and family where appropriate) make decisions, especially when it involves consent to treatment or when to stop further treatment. This is a major area for ethical discussion and clinical guidance (Section 2.5) and staff training (Section 7.2).

The planning process and decision making

"...their disease trajectory may be a long one, over many years of relative stability, with episodes of ill-health occurring at irregular and unpredictable intervals. A dilemma regularly faced is the appropriateness of treatments or interventions... One of the regular exercises we conduct is an annual review. This provides an opportunity to sit down, in a relatively formal manner, to discuss a number of issues including what future decisions might be helpful to be planning for now. The young person – if at all possible – with parents and a member of their key worker team will meet with the Head of Care, a doctor, a member of the Family Support Team and whoever else the family may wish to involve. This meeting enables the hospice team to meaningfully predict future input that may be required. It also provides an opportunity to focus on difficult issues around life, death and treatments which the family may not previously have voiced, or which

they may have been thinking about quite deeply. Often they have not felt able to initiate the subject themselves."

Rose Midson, Head of Care, Little Haven

In the case of young people with a learning disability, they should also be encouraged and enabled to participate in decision making as far as possible. It may be that they lack the capacity to make the decision in question or even be aware that a decision is being asked of them. It is essential that they have independent advocates. Advocacy services should be readily available to any young person accessing palliative care services. For young people who have become intellectually impaired and can no longer express their views, the knowledge of parents or long-term carers is invaluable.

5.8 Spiritual needs

Many professionals find spiritual care the most difficult aspect of holistic care. When adolescence and/or cultural diversity add an extra layer of complexity, it presents an enormous challenge. Powerful feelings of anxiety, guilt, fear, isolation and hopelessness can arise as questions on the meaning of life, pain and suffering, unfairness and punishment remain unanswered. Sometimes these worries remain unspoken as the young people, parents and healthcare workers evolve complex webs of avoidance, collusion and mutual protection (Goldman et al in press).

Spirituality is implicit in the definitions of adolescence and in the developmental tasks outlined in Section 3.2. These include achieving a sense of self as a worthwhile person, developing an internal set of guiding norms and values, and the ability to think logically, construct hypotheses, use ideas and imagination and distinguish from each other fantasies, ideas, beliefs, probabilities and possibilities. For some young people in some families, the questions are answered by faith and religious beliefs that may have been an important part of the context in which they live (Brown 2000). However, the turbulent years of adolescence, in the struggle for independence from parents, may involve a rejection of the older generation's beliefs and values. Tacit

assumptions that children's beliefs will be the same as their parents should be avoided and their own personal beliefs acknowledged and respected.

In the face of a prospect of an early death, the idea of identity and what a person might become are very significant. Young people need to explore the 'reasons' for their illness and impending death (Hart and Schneider 1997). Many face the prospect of increasing physical or cognitive deterioration and some are living in the knowledge that there is not much time left. Despite this uncertainty, many young people continue with the notion of making their mark and achieving something in the world. For many there is little potential and they may express a hope for some kind of spiritual continuity, even if it is not based on a specific religious belief.

Appropriate responses may not be immediately obvious, other than to reinforce the sense of worth and continuity and to provide opportunities to discuss and explore feelings in a safe and confined way. There are several factors to take into account and the first is the young person's own choice and expressed need. Traditionally in this country, palliative care is based on Christian ethic and practice, which may not be appropriate and professionals must be aware that young people may not have decided on a religious commitment or have the maturity to refuse what is on offer. Great sensitivity is also required in determining how to meet the spiritual needs of young people from other faiths and cultures (Bacon 1996). A further important issue is the care of young people with sensory impairments or learning difficulties, who may have little ability to formulate and express spiritual needs and with whom establishing communication is difficult.

5.9 Support for parents and siblings

Young people who have experienced cancer or leukaemia suggest that families should be forewarned of possible non-medical effects, not only practical issues, but emotional ones too. They list severe disruption to the family routine, difference of opinion between parents on the best form of treatment, anger and loss of friends. They propose that every family should

have someone to talk to who is not part of the clinical team and to whom they can voice their fears and express their anger.

It is reported that siblings sometimes complain of feelings of deprivation, displacement, injustice, anger, loneliness and vulnerability and that care is focused on the sick sibling, leaving parents with insufficient time for them. However, this is not inevitably the case and other researchers report positive and adaptive responses. These conflicting findings are analysed by Bluebond-Langner in "In the shadow of illness: parents and siblings of the chronically ill child." (1996). Bluebond-Langner, in this research report, suggests that analysing the deficiencies in the lives of well siblings is not the most constructive way of understanding the impact. Rather, it is important to look at well siblings in the context of the family, examining how they view the illness and how they relate to their ill sibling and parents. In this way, we can see how they interpret their experiences over the course of the illness and what shapes their views and responses. Any clinical intervention should then be based on understanding this experience. Not all psychosocial problems are amenable to change. "Much of what the well sibling feels in the way of lack of attention, disruption to family life style, concern for the ill child, and fear of the illness's consequences may be not only unavoidable, but also appropriate" (Bluebond-Langner page 266).

5.10 Providing opportunities for everyday activities

Most young people want to be fully involved in leisure activities and the social scene. For the younger people in this age group, school is a very important source of friendship and leisure. Schools (and local authorities) need to make provision for social contact, development of life skills and access to community facilities, as well as access to the curriculum. The advantage of special versus mainstream schools (in terms of opportunities, empowerment and quality of life) still requires more debate (Alderson 1999; Alderson and Goodey 1998; Noyes 1999). People with disabilities can and do participate widely in sports, though sport education can be neglected in schools. Parents should be encouraged to see the benefits of leisure activities

and not only as secondary needs to education and physical treatment. They can give enjoyment, overcome apathy and depression and ensure that the young people have a higher expectation of themselves.

Practical examples of how opportunities for socialising can be provided and friendships encouraged are given in the box below. The use of the internet can also become an invaluable support, especially for those isolated geographically or by the rarity of their condition. However, whilst recognising that young people can receive support from others with similar health needs, there is evidence that they can find this depressing as they watch the health of their friends deteriorate. They also need to minimise feelings of separateness and isolation by being encouraged to participate in activities with young people who are well.

Opportunities to increase independence and meet peers.

Two practical examples

Rachel House teenage weekends . . . are structured to promote and facilitate choice, privacy, positive self-image, independence and self-management, while enabling young people to self-advocate their hopes, needs and fears. The environment is safe and supportive, with help and advice available, but only given at the request of a young person. The weekends include multi-sport activities, themed evenings, group discussions and issue-based workshops, with the young people having control over the context and structure. An important objective is to provide the opportunity to make new friends, thereby widening their own support networks.

Sharon Ballingall, Rachel House Children's Hospice

The Tak Tent Youth Project offers a social outlet in a supported environment, specifically aimed at, and geared towards, 16-25 year olds with cancer, including those receiving palliative care, their siblings and friends. There are several strands to the support, including the opportunity for young people to meet and talk in a supported environment. These young people often perceive themselves to be socially

excluded, perhaps because of hair loss, or perhaps because their friends have 'disappeared' and they feel rejected and isolated. Evening meetings provide an opportunity to make friends and support each other. On the 'indoor night' the group decides the activities, which have included team-building games, arts and crafts, watching videos and guest speakers. Another night the group goes out to a social event, such as bowling or karaoke, which provides access to ordinary social activities.

April Walker, Youth Co-ordinator, Tak Tent Cancer Support

5.11 Sexual issues

For many young people, personal expectations relating to relationships and sexual issues are a major concern. Clearly sex education is important for all young people, as is access to sexual experiences. It is reported that parents are often surprised that their adolescent terminally-ill child has sexual feelings. These young people are often isolated from their peers and sources of normal adolescent information and discussion. Staff in residential units (hospices and hospital wards) are sometimes approached for advice on such subjects as masturbation, accessing videos and finding a sexual partner, and this can be a distinct challenge for staff trained in paediatrics. This is an area that only recently has been openly discussed (Joseph Rowntree Foundation undated).

For several disorders, appropriate information and informed discussion about sexuality and fertility are essential. For example, evidence from an adult cystic fibrosis clinic indicates how, where, when and with whom discussions will take place for each of their young male patients. There may also be issues surrounding fertility at a younger age, when consent may be more complex. For young people with cancer, there may be questions of sperm banks or harvesting unfertilised eggs and the potential for delaying the commencement of treatment.

5.12 Equipment and housing

There are still problems over equipment provision and replacement, which cause distress to young people and their families (Audit Commission 1996; Glendinning and Kirk 2000; House of Commons Select Committee 1997). There is sufficient evidence on the natural history of diseases and knowledge of disorders to allow forward planning, so that equipment and modifications are in place as a young person develops or deteriorates. Our evidence suggests that lack of good communication between Health and Social Services, bureaucracy and/or a crisis intervention attitude are the main causes. There is still fighting over which budget should be responsible. Some of our evidence even suggests that there is delay in providing equipment in the expectation that the young person will die before the equipment becomes absolutely necessary.

In some places, occupational therapists work jointly with Health and Social Services, providing a service to cover developmental assessments, treatment and provision of equipment and adaptations. This is perhaps ideal from the family's point of view, as there is only one therapist to deal with. If pooled budgets are not available, families should expect good communication between professionals and a cohesive service.

As shown in Section 4.7, many young people have a desire for independence, even for part of each day, but are unable to 'escape' from the close protection of a parent or other carer. This might be possible for some young people, through the provision of special equipment, which allows them to control their environment from a wheelchair. Other equipment, such as self-operated hoists and turning beds can also enhance a young person's independence, while reducing the burden on the family.

Planning ahead – an example from duchenne muscular dystrophy

Post-school, the majority of boys seem to be stuck in the house. The vast majority are accompanied by another adult, which is not really the case for most adolescents who are more independent and are allowed to be in the house alone. To feel a sense of independence in moving around the house by themselves, it is vital that they have such equipment as environmental controls which allow them to lock or unlock a door, switch on lights, use the telephone etc. Perhaps, if parents were assured that the correct equipment was in place and that the boys would be safe, they would feel more secure about allowing them this independence.

Veronica Watters, Family Care Officer MD Campaign

The issue of housing has also become emotive. Some families believe that the statutory authorities stall on house modifications, in case the young person dies. It is also a stress for families knowing that if their child dies and they wish to move house, they will need to pay back any grants. The "Homes Fit for Children" initiative highlights that means testing for these families is unfair and does not take into consideration all the other costs incurred whilst caring for these young people (Oldham and Beresford 1998; Joseph Rowntree Foundation 2000, Beresford and Oldham 2000). It also highlights the needs of the rest of the family with regard to space and privacy.

5.13 Appropriate environments for young people

Many small studies have been carried out, asking young people what they want in their surroundings when they are cared for away from home. The Teenage Cancer Trust (2001) has analysed data from its teenager units and several children's hospices have looked to their adolescent patients for advice. Their findings show that young people with very serious or life-threatening conditions are no different from their healthy peers. A general review of the literature on the ideal environment for young people can be found in "Youth Matters" (Viner and Keane 1998).

Young people want privacy to be alone when they feel like it and personal space to pin up posters and cards. They often find existing toilet and washing facilities distressing because of lack of privacy and lockable facilities; they ask for somewhere to shower, shave, dry hair and apply make-up.

At the same time they also need opportunities for peer interaction. Young people complain that there is not enough to do, especially in evenings and at weekends. They suggest a recreation room with table tennis and pool tables and other games, televisions, videos, stereos and computers with access to the internet. They would also like dispensers for cold drinks and coffee (Viner and Keane 1998). They point out that they sometimes like to be noisy and that their hours do not always coincide with those of young children and older patients. They ask for decoration that is not childish, but more like a family home.

5.14 Appropriate residential homes

Not all young people are able to live in a family home cared for by parents. Some are in residential care in nursing homes, both in the commercial and voluntary sector. As numbers increase, occasional new services are being developed to cater for particular groups. Two examples are described below, one for young people with Batten disease with both progressive physical and mental impairments, the other for people with moderate and severe HIV related brain impairment (HRBI). New treatments

have now changed the pattern of HIV symptoms and Patrick House has closed. But the services provided and the lessons learned have been taken up by similar hospices and residential facilities elsewhere in the world.

Patrick House: home for those with HIV related brain impairments (HRBI)

The aim at Patrick House was to provide homely, welcoming and comfortable accommodation where supervision could be provided in an individualised manner. The following principles were upheld:

- Individualised assessments
- Individualised care plans
- Flexibility of care: to meet the changing needs of each resident
- Independent living: residents encouraged to live to their maximum capability of independence
- Quality of residents' lives to be emphasised
- Dignity for each resident to be respected
- Primacy of residents' interests to be maintained at all times and advocated when necessary
- Care and advice is given to those affected by the resident's HRBI, for example partners, parents and friends.

Taken from de Villiers, Patrick House, Philosophy of Care

Heather House: Nursing Home, Activity and Resource Centre

SeeAbility is building this home in Hampshire to provide services for young adults with a visual impairment and degenerative illness, focusing particularly on young people with Batten disease, aged 18 to 35. It will provide nursing and social care services for 16 young adults, an activity and resource centre, a family/carers' support service that will include sharing ideas, concerns and issues, an outreach service for support in the community and consultation for professionals and on-going research in the area of degenerative illnesses affecting young people.

The aim is to offer:

- A home-like environment, with nursing activities undertaken as support to enable residents to live as active a life as possible.
- Activities to stimulate and encourage a sense of achievement; to emphasise quality of life; to minimise degenerative effects.
- Long term, palliative and terminal care.
- Involvement of family and friends in the life of the young people.

Taken from SeeAbility Heather House brochure

Summary of 5

- Co-ordination of care, particularly in the community, is required. A multi-disciplinary community team for young adults with life-threatening disorders would be an appropriate development. *[Section 5.1]*
- Respite is essential, but schemes and provision for this age group are scarce. *[Section 5.3]*
- Clinical psychologists should be core members of caring teams, so that support is available as and when needed without long waits. *[Section 5.4]*
- The very act of bringing young people together is in itself a support and an aid to care and treatment. *[Section 5.4]*

There are problems over equipment provision and

- replacement, which cause distress to young people and their families. Pooled budgets and jointly employed occupational therapists are ideal. *[Sections 5.5 and 5.12]*

Young people should expect to be involved in decisions,

- including consent to treatment and refusal of treatment and legally should be involved if they are competent. *[Section 5.7]*

Leisure activities should not be viewed as secondary to

- education and physical treatment. They can give enjoyment, overcome apathy and depression and ensure that the young people have a higher expectation of themselves. *[Section 5.10]*

6. The transition from paediatric to adult health services

6.1 Transition in health

In this Chapter, we are discussing only transition in the health services, not transition in Social Services and Education, which is covered by regulations laid out in the Code of Practice (1996 Education Act) and which is currently being updated, following a review of practice. By singling out transition in clinical services, we are not suggesting that co-ordination with other agencies is not essential. In fact, the distinction between health service responsibilities and expertise and those of other services is often not clear. A major task is to work effectively across boundaries between agencies.

Within the health service, there are no regulations for moving patients on from children's to adult services, though practices for young people with chronic disorders have been examined and guidelines developed following a workshop at the Royal College of Physicians in 1995 (Kurtz and Hopkins 1996). Young people in particular specialities have also been surveyed for their views (Helps et al 2000).

Transition remains a major issue, despite efforts to tackle it over the past ten years. Young people and their families still report feeling abandoned [Section 4.3]. The evidence suggests that transition is a daunting process for most young people with disabilities and chronic disorders, and for their families. It can be traumatic for some.

6.2 Why is transition failing?

We have identified seven possible reasons why the transition process is inadequate.

- Family's attachment to paediatric service.** Most young people have been with the same paediatrician and paediatric services since diagnosis, which can be 18 years or more. The family has often developed a strong attachment, with faith in the long-term knowledge of the paediatrician, knowledge of how the system works and trust in the staff. It is no wonder that they feel apprehensive about learning a new system with different personnel, different methods, different places and staff who know little of the history. Families often resist the transfer. Sometimes a transfer is arranged and fails and the young person comes back to paediatrics. Even after apparently satisfactory transfers to adult services, the families often come back to paediatrics to 'check things out' feeling that paediatricians can assess things in the light of long-term knowledge.
- Paediatrician's reluctance to make the transfer.** "A paediatrician may look after a child with chronic illness or disability for many years, watch him or her grow up.... It would be a strange paediatrician who did not sometimes feel a degree of emotional attachment and involvement beyond that required for the technical delivery of medical care." (McConachie and Jaffa, 1996). For parents, gradual separation with continued contact into the indefinite future is possible, but for the paediatrician and the paediatric team, transfer is formal and final. Many are also worried that they are handing on to a less good service. As a result, they sometimes delay the process.
- Fragmented and impersonal health care.** Paediatric services are multi-disciplinary and supportive. They are not perfect, but certainly more comprehensive than adult services, where there is a greater expectation that people will find their own way round the system. There is a widely-held view that adult medical services are impersonal and even hostile; many families anticipate that the young person alone will not be able to cope and get the best from the service. Most also feel that parents will be excluded since the focus will be on the individual patient rather than the family (McConachie and Jaffa, 1996). These views might be somewhat unfounded, but they certainly affect the process of transition.
- Poor co-ordination of clinical services.** In paediatrics there is a general or community paediatrician who has an overview of all the strands of care – and these can be considerable and complex for many young people. In adult services there is no equivalent doctor to take on the overview role. So, at a time when services become more fragmented, there is no one doctor to co-ordinate and maintain the holistic quality.
- No equivalent adult service.** For rare disorders, especially degenerative conditions and also some congenital and learning difficulties, when young people outlive their predicted life expectancy, there is no equivalent adult service to transfer them to. There are no adult physicians specialising in these disorders and no community services (nursing or therapeutic) with expertise and time. Families can feel as though they have been cast adrift.

- **Transfer at a time of great instability.** Because of improvements in survival time, many young people are now living into their late teens. Families are faced with transfer at a time of great anxiety about the young person's prognosis. This might mean that families are faced with the terminal phase without the support of the known team.
- **Lack of assessment of young person's emotional readiness.** Some of these young people can be profoundly insecure and to move them into the adult services without considering their individual emotional needs is to plunge them into a bereavement situation in which they suffer separation anxiety, loss of identity, loss of self esteem and loss of significant relationships.

6.3 Some solutions

6.3.1 Existing models

Clearly the solution to these problems is very wide-ranging, involving a range of professionals in many disciplines. Some approaches are described in this example.

Working for transition

The adult services do not replicate what we do. A long transition time is therefore necessary in order for the family to adjust and to look at alternatives to fill the gaps, such as Social Services and the voluntary sector. From a nursing point of view, we discuss with District Nurses well in advance. We may transfer to a combination of services such as the District Nurses, the local adult hospice/community team (for nursing care) and the Learning Disability Team for support for the family. We make joint home visits and hold professional networking meetings, for often it is not just nurses, but also physiotherapists, occupational therapists, dieticians etc who may be transferring care.

Sue Wates, Community Children's Nurse, St George's Hospital

An example of a condition in which a large proportion of the patients reaches adulthood is cystic fibrosis. The care of these young people has become a special interest for some adult respiratory physicians and the transition process has been examined and monitored. Although the adult environment differs considerably from paediatrics, (possibly longer waiting times for tests and appointments and less contact with the consultant), most young people eventually manage the transition successfully. This is a time when young people are seeking independence, and are in the process of developing self-care, supported by parents and hospital. This represents a major change in a young person's life and the importance of starting the process early and being patient if it takes a long time were stressed in the evidence.

Length of the transition process: a model from CF

"Following the appointment of a chest physician with an interest in CF and two respiratory nurse specialists, we set up a joint clinic involving the whole multi-disciplinary team to which the young people are invited when they feel ready. After a period of attending a joint clinic, at a time of their choice, they are transferred over to the adult team. The period of transition works very well, with the two teams of community nurses liaising closely and the adolescent being given time to build up confidence in the new team. This can take anything from a few months to a year or more."

Mary Lewis, Senior Community Children's Nurse,
The Lifetime Service, Avon Health District

Having in place a liaison nurse, or another professional in a similar position, with a particular remit for the adolescent patient can be extremely helpful, as the channels of communication can remain open for patient, family and professional. It does not feel that one team is 'shutting the door' on a patient they may have cared for over a considerable length of time. The primary health care team could also be involved more in support of their young patients making this transition.

The cystic fibrosis model might be suitable for some other disorders and we have been told that it is being considered for neurological conditions. At a minimum, it appears that most young people attend a clinic held jointly with the adult physician before the transfer takes place, though the evidence suggests that this is probably inadequate for most young people. In cases of rare 'childhood' disorders, some paediatricians remain involved in the care and maybe this is the ideal, especially when life expectation is short.

For young people with other conditions not formerly recognised in adult services, there is some evidence that the best way forward is to develop a central specialist service for them. For example, an occasional young adult with congenital heart disease may be a case of interest in a district, but may receive sub-optimal management because of lack of experience and wisdom to ask advice (Somerville 1996). They can be followed at peripheral clinics more convenient to the home, as long as there is a specialist centre at which further information and advice is available.

6.3.2 Framework to guide the process

We received evidence suggesting that it is helpful to have an overall framework as guidance for the transition process, but which allows flexibility for each individual young person. It was proposed that a first stage might be identified, ranging from 13 to 17/18 years, with the goal of transferring the young person from paediatric to adult health services. Then another goal could be set to increase a young person's independence by the age of 25. What is most important is that this transition phase is planned with the young person and set out for the primary care team, consultants, all other professionals involved and the family to work through, so that everyone has a clear direction. Having a completely open ended process is unsettling. It does not help a family to accept change and allows them to linger unsatisfactorily in Paediatrics.

Research from the Cystic Fibrosis Trust (Powncenby 1996) suggests that crucial elements in the actual transition process are:

- Written information about the adult unit, available at an early stage
- An opportunity to sample the new facilities and staff by way of combined paediatric and adult clinics.
- An introductory visit to the ward area, together with an accompanying paediatric team member.
- Joint visits by paediatric and adult nurses and therapists.
- Attention to the young person's feelings post transfer to help them to settle into their new environment.

Summary of 6

- Transition from paediatric to adult services remains a major problem. *[Section 6.1]*
- Families do not want to lose the strong attachment they have built up with the paediatric team, and anticipate impersonality and a less holistic family-based approach. *[Section 6.2]*
- Paediatricians may be reluctant to make the transfer, because they are worried about the young person's clinical stability and prognosis and because there are no adult physicians specialising in the disorder. *[Section 6.2]*
- Research suggests the following principles for the transition process:
 - An overall framework for guidance, so that the process is not open-ended
 - A plan made with the young person and family and set out so the primary care team, consultants, therapists and all involved have a clear direction
 - An early start and a 'no-rush' policy. *[Sections 6.3]*

7. Needs of professional staff and carers

7.1 Intrinsic skills

Some professionals admit that they find this group very difficult to work with (Viner and Keane 1998). To work well and comfortably with young people, all staff (and this includes volunteers and housekeeping staff in residential settings) need some intrinsic skills. It may be possible to learn some of these skills, but others are more intangible and may be difficult to learn. These skills include:

- An interest in and commitment to the adolescent age group
- The knack of communicating and empathising with young people
- The ability to work in a multi-disciplinary team, especially in terms of sharing information and accepting overlapping boundaries between different professions
- An awareness of boundaries between personal and professional involvement.

7.2 Education

7.2.1 Current expertise and networking

Many professionals have built up considerable expertise through practical management of young people. They are very scattered across the country and working in many different types of service. There is a great need for networking, to bring together individuals to pool their experience and build up a shared knowledge. This has already started, though limited to small spheres. For younger adolescents, umbrella or professional organisations in paediatrics (e.g. the Paediatric Palliative Care Special Interest Group of the Royal College of Nursing) might provide a forum for a special interest meeting. The volun-

tary sector is also active (e.g. Association of Children's Hospices and ACT) and their work is tackling the needs of older adolescents and young adults too. The Teenage Cancer Trust has a Multidisciplinary Forum, which hold meetings for 'problem solving' discussions.

Multidisciplinary Forum sponsored and supported by Teenage Cancer Trust

There are many isolated groups of professionals working in this field, all seemingly struggling with the same difficulties in this growing speciality [cancer care for young people]. It was recognised that there was a need to establish an active group which could work together in this development.

The Forum aims to:

- Provide support for professionals
- Promote an awareness of this patient group
- Promote the philosophy and principles of caring for these patients
- Provide a 'voice' for teenagers and young people with cancer.

It does this through quarterly meetings, open discussions dealing with challenges of caring for these patients, study days, conferences, participation in research, provision of central point for collection and dissemination of research findings and provision of a focal point for expertise and advice.

Taken from TCTMDF leaflet

7.2.2 Sources of staff

Those who choose to work with this age group may come from a variety of sources and will bring a wealth of experience from different types of basic training. For instance, even from one profession, for example nursing, it would be relevant to have nurses with a background of working with children or adults or people with mental health or mental handicap problems. Of prime importance is a clear understanding of the developmental stages of normal adolescence, which is basic to an understanding of the unique psycho-dynamics of young people. The training might be easier for children's nurses, who are accustomed to dealing with a changing physiology and psyche. On the other hand, there are special circumstances for particular diseases, e.g. some sorts of cancers that mainly affect adults, that would require staff with adult training.

Recruitment of nursing staff in this area of care is problematic. Greater emphasis on young people in the training modules would be helpful, as would placements in locations where young people are cared for. In Southampton University Hospital Trust a possible placement for D and E grade nurses is Naomi House (children's hospice), which has proved a popular development. Lastly, many young men, especially those cared for at home by their mothers, are totally lacking in male company. Hence it would be advantageous if a mixture of male and female staff were available. However, difficulty is reported in attracting male staff into palliative care for children and young people.

Young people themselves say that they prefer a young person as a care assistant, someone who has a close understanding of their needs. Some, who are in control of their own care package, succeed in finding assistance of this kind. However, there are dangers that such young assistants may not be able to cope emotionally. Some young people choose to work with those with disabilities through the Community Service Volunteers scheme. Elsewhere in Europe, young people are more widely used, as in this example.

Young carers

"There is a real need for more young people to work closely with these disabled youngsters. I was very impressed when I visited Denmark recently to see the carer system there, which encourages people to take a year out to work as a carer after completing their careers at school.

Dr K M D Bushby, Reader and Consultant in Clinical Genetics,
University of Newcastle

- Management of non-adherent behaviour
- Management of emotional involvement
- Counselling
- Advocacy

7.2.3 Basic competencies for all disciplines

All (and here we include professionals in health, social work, education and pastoral care) who work with young people with life-threatening disorders need a wide range of basic knowledge and competencies, providing them with skills that might be over and above their specialist training. These should include education in:

- The developmental stages of normal adolescence
- The rights of young people, issues around consent and ethical dilemmas
- The effects of loss and bereavement
- Working with reference to families, partners and close friends
- The needs of siblings
- Cultural diversity
- Spiritual needs – religious and secular approaches
- Liaison with school and college
- Communication skills, focusing on particular issues, in addition to listening skills and non-verbal communication

7.2.4 Resources for training

Training needs for all the major groups of professionals who work with young people remain considerable. All training takes time and funding and this needs recognition and protection. In districts where care for this group of young people is not undertaken by a specific team, such training should be open to professionals and carers who may only have a few such clients on their caseload. The training needs of associated care personnel should not be forgotten.

7.2.5 Location of practical training

The nature of palliative care in young people is that life-limiting illness can last for many years. Individuals will require many types of care, delivered in many environments – home, school or college, hospice, respite centre, nursing home, outpatient department and acute ward. Training should be designed to reflect this and valuable educational links should be developed between primary health care teams, community and hospital paediatric teams, children's hospices and adult palliative care services.

7.2.6 Education in palliative care of young people

Because of the wide-ranging experience required, it will perhaps be necessary to concentrate on the principles that are common to all young people with a terminal condition. The following table is an outline proposal from a doctor, but the principles could be widely applicable across the professions involved in palliative care for this age group.

Experience for those specialising in palliative care for young people

Essential

Experience in the community, where young people with a chronic handicap are cared for at home, to gain experience of care in many locations, an insight into family problems and the diversity of professionals involved.

Experience in a specialist unit providing care for diseases such as cystic fibrosis, muscular dystrophy or cancer, where care is typically co-ordinated from a hospital.

Attachment to a children's hospice or an associated primary care team to gain exposure to a wide cross section of life-limiting conditions and to have the opportunity to spend time with the parents.

An opportunity to acquire counselling and communication skills (maybe by an attachment to psychology or to a palliative care team).

Training placement to gain knowledge of physical symptom control, perhaps with a paediatric palliative care team (few and far between) or an adult palliative care team (but techniques learned will be of less use for young people). Distance learning is possible.

Desirable

Familiarity with principles of psychology and particularly family therapy.

Training in bereavement counselling or experience of bereavement groups.

Attachment to a clinical genetics team.

Encouragement to carry out research – good opportunities for doctors and nurses to work together.

For nursing, educational guidance and frameworks already exist to enable nurses to learn about the palliative care needs of young people. The division between children's and adult services is mirrored in the separation between adult and children's educational programmes. However, the requirement for children's nurses to be prepared, at registration, to care for adolescents and for adult nurses to care for young people from 18 years is explicit in curricula guidance, as is the care for people with complex, life-threatening illnesses and an introduction to multi-professional and inter-agency working (ENB 2000).

Examples of educational opportunities for qualified nurses specialising in this field include courses in palliative care for children or adults and on nursing adolescents. The NHS Cancer Plan (2000) includes £2 million for additional training and support for community nurses in palliative care. There are also scattered opportunities for adult nurses, initiated as a result of Trust business plans for transitional services, for education around specific groups of young people, now living into adult life (e.g. congenital heart disease).

The ENB has provided the guidelines for nurse education in this field. What is largely missing is the implementation, both by those commissioning and those providing education. In particular, those planning both pre-registration and relevant post-registration education for nurses need to address issues around the impact of the transition from paediatric to adult services and the other problems encountered by young people receiving palliative care. The time given to topics relevant to this age group and also the content of sessions varies between the different institutions offering these courses. A research project has been set up at Leeds University, under the auspices of the ENB, to carry out an evaluation of educational preparation for cancer nursing and palliative care for children and adolescents.

Some of the courses currently available provide positive links between paediatric and adult services and are designed to be multi-disciplinary, so that they can be accessed by those in other professions, such as social work, occupational therapy or pastoral care. Teams become more effective when (in addition

to their core skills) relevant training is shared and collaborative approaches worked out. An example comes from Acorns Children's Hospice Trust, which has an established training programme around issues of loss, grief and bereavement. Spiritual help, from both religious and secular approaches is covered. Where appropriate, community and religious leaders are invited to facilitate training days on the care of minority groups, such as Moslems or Sikhs. The Acorn's programme also covers working with siblings, cultural diversity and ethical dilemmas. They have a two-part course entitled 'Death and dying: working with adolescents'.

Front line professionals need training in assessing bereavement. There are appropriate methods already in use and courses have been devised (for example by Child Death Helpline). Bereavement counselling requires specialist training and may be provided by specially qualified psychologists, social workers, other mental health specialists and trained volunteers (ACT and RCPCH 1997).

7.3 Support

7.3.1 Individual and team support

Within an organisation (e.g. a children's hospice or a community care team), emotional stress is high and individual staff members may find their work emotionally draining. Often a staff member knows a young person very well, having cared for him over months or even years. In their own time, young people will need to explore their feelings and work out reasons or meanings for their illness and untimely death. If the staff involved have not had the opportunity to develop self awareness and an understanding of the possible impact of this work on themselves, there is a danger of burnout or sub-optimal patterns of work. (ACT and RCPCH 1997). Regular and timely support is essential for staff, including personal supervision and team building exercises. Access to an outside organisation, e.g. a local Psychology or Psychotherapy Department, or a chaplaincy team for group or individual work should also be built into the system.

In palliative care, individuals sometimes have to make quick

decisions or respond at once to a patient's question. Reflecting on actions taken, in the form of debriefing, can be a positive reassurance and a helpful way of developing practice and protocols through experience.

7.3.2 Vulnerable times

There are particularly vulnerable times, for instance personal bereavement of a team member or after heavy periods of terminal care. There is evidence that young people reaching the terminal phase of their illness choose one person as a 'confidante' and this person may need considerable support. The managers need to be alert to additional stress and allow 'time out'. Managers also need to look out for families becoming over-dependent on one person, so that it is difficult to maintain professional boundaries whilst being perceived as the 'family friend'. Staff input may need to be shared at times, if this is proving problematic

The age of the professionals may also be problematic, when young staff may be little older than many of their patients. The need for staff support in this situation is intensified. Young people may seek them out, finding them less threatening and easier to relate to than mature staff. However this may lead to personal-professional boundary problems which prove inappropriate. Similarly, older professionals may also have boundary problems, in that they may respond inappropriately to young patients, as if they were their own children (Jackson 1993).

Summary of 7

- Current expertise is considerable, but is scattered geographically and across different agencies. There is a great need for networking. *[Section 7.2.1]*
- Training needs remain considerable. All training takes time and funding and this needs recognition and protection. *[Section 7.2.4]*
- Wide-ranging experience is required and training should be designed to reflect that care is delivered in many environments – home, school/college, hospice, respite centre, nursing home, outpatient department and acute ward. *[Sections 7.2.5 and 7.2.6]*
- Multi-disciplinary palliative care courses for this age group are just developing, covering a wide variety of topics, including loss and bereavement and ethical and legal issues. *[Section 7.2.6]*
- Regular and timely support is essential for staff, including personal supervision and team meetings. Access to an outside organisation, such as a Psychology Department or Chaplaincy team should be built into the system. *[Section 7.3.1]*
- Personal-professional boundary problems may result in inappropriate care. *[Section 7.3.2]*

8. Concluding guidance

8.1 Principles for care

In providing care for young people, the following principles have to be taken into account. They will impinge on how and where services are provided and, most importantly, they will have important implications for staff provision and training. To work appropriately with this age group, staff not only need to communicate well with young people, but also have a knowledge of adolescent development, family dynamics, the law, ethics and minority cultures.

- Young people should be involved in choices and decision-making at every level.
- All young people, whatever their age, are entitled to confidentiality.
- Flexibility and anticipation of needs are important principles, especially at the time of transition from children's to adult services and at the terminal stage.
- Continuity and support should be provided at times of change, since young people with life-threatening disorders can feel very vulnerable.
- All working with young people should be aware of the tension between dependency and independence, which may be strong for this age group.
- The family of a young person should be included in the care plan (with the permission of the young person) more than is usual in adult services. Even after reaching the age of majority, many will be tightly linked to their families emotionally and practically.
- Some young people will have partners, who should be included in the planning.
- Psychological and spiritual needs should always be included as part of the service, and be available on a one-to-one basis.

Review of care packages should be frequent, since each young person continues to grow, develop and mature, while deteriorating clinically.

Changing needs for equipment should be assessed and dealt with rapidly, since it is not acceptable for young people to be using out-grown, inappropriate equipment or for families to struggle with inadequate equipment.

A desire for independence and opportunities to participate in activities that other young people do (including sexual experiences) are natural for this age group and should be incorporated in care plans.

Life goals, including education, should be included in planning.

Opportunities for shared experiences should be provided, since young people gain much benefit from the support and camaraderie of their peers.

An environment appropriate to the needs of young people should be provided.

8.2 Service components

Provision is extremely complex, with interventions from many professionals in Health, Social Services, Education, youth services and the voluntary sector. Services cross many boundaries within paediatrics, and between children's and adult services. Young people should expect a service with the following components.

- Symptom management of the underlying condition, provided locally and ideally by an experienced multi-disciplinary team, with supervisory input from either a paediatrician or an adult physician (or both) with knowledge of the underlying principal condition.
- Close and regular involvement of an appropriately-trained primary care team, caring for inter-current events and supporting the young person and all members of the young person's family. The general practitioner to be provided with all information necessary to monitor all clinical interventions.
- A named key worker to act as advocate/supporter for the young person.
- Information, supplied to young people to enable them to make informed decisions.
- Appropriate information and support networks for parents, siblings and partners.
- Practical support for the families of young persons with severe intellectual and physical impairment, to include regular planned respite appropriate to clinical and social needs, both in and out of the home and where possible together with peers.
- Occupational therapy available as a core service.
- Access to, and maintenance of, appropriate equipment, at the right time and through a central source.
- Clinical psychology available as a core service.
- Spiritual care from front-line staff and referral as appropriate.
- A plan, discussed and agreed with the young person, on procedures, time scale and support during transition to adult services.
- Advice and support for housing, grants, benefits, equipment and employment of carers.
- Facilitative support to continue in education and to pursue other life goals and relationships.
- Terminal care in an appropriate place, with a choice provided.

8.3 Implementation

A body of evidence was received on the benefits of bringing young people together, especially in terms of mutual support and as an aid to care and treatment. Isolation and lack of opportunity for peer support was highlighted by our Young People's Forum. This is not easy to resolve. Individual support for young people in this position should be built into the care system and, whenever possible, young people should be brought together with their peer group, for instance for respite and recreation. However, widespread segregation of this age group would have great implications for the appropriation of personnel and resources across the palliative care and community services and has been rejected as a general principle. More realistically, the Working Party believes that commissioners and providers of services should concentrate on the planning of flexible provision, with the emphasis on separate and differing needs rather than on separate services. Some needs may be met by the reorganisation or expansion of existing services in a resource efficient way. Others may need to be considered on a sub-regional basis.

In terms of implementation of good service provision there are two major difficulties that will have to be overcome. First is the small number of potential clients in this age group at a local level. Second is the transition from paediatric to adult service providers, which necessitates the involvement and possible joint working of staff from the two areas. Together these complicate the task of introducing effective action. One possible way forward might be to have a link person to coordinate the range of services and providers, including the voluntary sector. This needs further exploration, especially in terms of liaison workers already in post in the adult sector.

There is a shortage of professional staff trained to provide the palliative care needs of this age group. Existing courses, both in paediatrics and adult services should be expanded to cover the particular issues raised in caring for young people. The subject matter seems ideal for multi-disciplinary courses.

This project has brought together, for the first time, the people involved in the care of young people with life-threatening conditions, pulling together a body of knowledge on the palliative care needs of this age group. Commissioning bodies now need to take this forward by measuring the need across all disorders in their locality and including it in their specialist palliative care strategies.

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Appendix 1. Current provision for this group

Provided by Children's & Related Services

<p>Multi-disciplinary district health services, based on Child Health¹ General & community paediatricians² Community children's nurses Diana Nursing Teams Physiotherapists Occupational Therapists Dieticians Speech and language therapists</p>
<p>Specialist Paediatric Services, mainly based in regional hospitals³ Specialist paediatricians Clinical nurse specialists (including outreach nurses)</p>
<p>Wheelchair Services</p>
<p>Social Services for Children with Special Needs⁴ Disability teams Occupational therapists Paediatric social workers</p>
<p>Education and Youth Services for Children with Special Educational Needs⁵ Mainstream and special schools Educational psychology Hospital schools/home tutoring</p>
<p>Respite Services⁶ Social Services respite centres Health Service respite centres Children's hospices⁷</p>
<p>Terminal Care Community children's nurses with paediatricians and GP, multi-disciplinary teams e.g. Diana; outreach nurse specialists; familiar hospital wards; children's hospices</p>
<p>Voluntary Sector⁸ Children's hospices Support groups for disorders (e.g. Scope, Climb, CF Trust, CLIC, Muscular Dystrophy Campaign). Provision of specialist staff.</p>
<p>Religious and community groups</p>

Provided by Adult & Related Services

<p>No equivalent holistic district service⁹ Care remains mainly in the home¹⁰ GP and primary health care team¹¹ District nurses Community therapists</p>
<p>Specialist Adult Services, mainly based in regional hospitals¹² Specialist consultants in Neurology, Cardiology, Nephrology, Oncology, Respiratory Medicine Clinical nurse specialists (including outreach nurses)</p>
<p>Social Services for Adults Learning Disability multi-disciplinary teams Occupational therapists Social workers Wheelchair Services</p>
<p>Education and Employment Courses at Tertiary Colleges. Special needs officers at colleges and universities</p>
<p>Respite Services Inadequate provision¹³ Adult hospices¹⁵, nursing homes¹⁴ 2 hospices for young people in the planning stage¹⁶</p>
<p>Terminal Care District nurses and GP, adult hospices and palliative care teams¹⁷, nursing homes¹⁸, unfamiliar hospital wards</p>
<p>Voluntary Sector Adult hospices Support groups for disorders.</p>
<p>Religious and community groups</p>

TRANSITION

HOME

YOUNG PERSON

RESIDENTIAL CARE

TRANSITION

Notes

Children's Services

1. Most long term care is in the home, under the primary care team, supported by community paediatricians, occupational therapists, community children's nursing teams and the new Diana Nursing Teams (but these cover only 9% of health authorities), working together with specialist nurses and social workers from the regional centres. A few districts have established a multi-agency Children's Palliative Care Group, as advocated in the ACT/RCPCH guidelines (1997). These services generally cover the age range to 19 years.
2. The general or community paediatrician has an oversight of the many strands of care
3. Young people with rare conditions are often cared for by regional centres or tertiary hospitals and families usually welcome the opportunity to attend a specialist clinic, despite long journeys. For cancer, there are now several adolescent inpatient units, though they do not cover the country. The Leeds unit takes young people from 13 to 25 and has high patient satisfaction. When it comes to terminal care, there are more problems, with both paediatric and adult teams apparently finding it challenging to care for young people aged 16 to 25.
4. Social Services provide social workers and disability teams and are mainly involved in practical issues, arranging respite and organising equipment and house adaptations.
5. Special schools are valued by families. Access to physiotherapy, OT, nursing and medical advice is provided on site. However, they are being phased out in many parts of the country. In mainstream schools most help comes from welfare assistants. School health services appear to be less co-ordinated and scarcer than in special schools.
6. Respite which includes nursing care is provided by children's hospices and in a small number of NHS facilities up to the age of 19. There are sometimes also facilities for short breaks in the home.
7. There are 21 children's hospices, all small units with 2 to 10 beds. Most accept young people up to their 19th birthday. They report that between 26% and 54% of their patients are over 13 and the numbers are increasing. Some, despite their policies and the residential nursing regulations, are still caring for young people in their twenties. Some are adapting to increased numbers of young people by converting a room for their use or appointing a member of staff with a special interest. Resources are limited, though obviously staff try to ensure that activities are age appropriate. Acorns has a young person's section and Martin House is building separate facilities (see also note 16). Several have nursed young people with CJD.
8. Support groups for individual conditions are very helpful, e.g. Climb, Scope, CF Trust, branches of the Duchenne Family Support Group. MD Family Care Officers advise on home adaptations, finance, transport, counselling etc.

Adult Services

9. There is no equivalent of the general or community paediatrician in the adult sector. Care is often poorly co-ordinated from a number of disparate specialists without any coherent plan.
10. Most care remains in the home, supported by the primary health care team and community services, such as district nurses. There are no multi-agency teams equivalent to the children's community teams.
11. Primary care teams may have little expertise in these disorders. Frequently they are reactive rather than proactive.
12. For some rare conditions, such as metabolic disorders, there are no equivalent adult physicians, since these have hitherto been childhood conditions. Consultants in learning difficulties may take over the care of some young people with a life-threatening condition. For others, there are consultants in nephrology, neurology, cardiology, haematology, oncology, respiratory disorders and HIV. Many of these specialties employ clinical nurse specialists.
13. For young people over the age of 18, there is very little suitable respite provision, especially facilities with nursing care. For those with severe developmental delay or progressive deterioration the situation is totally inadequate.
14. Some nursing homes, often in the voluntary sector, offer respite places, e.g. Sue Ryder Care.
15. Adult palliative care services care mostly for elderly people with cancer. The average age of clients in adult hospices is 72 years. It is often difficult to cater appropriately for the needs of young people for respite care.
16. There is a small number of specialist hospices that offer services to young adults with HIV and AIDS.
17. Phoenix Lodge and Douglas House are hospices for young people up to the age of 40, both in the planning stage.
18. There is evidence from a small number of adult palliative care services that it is possible to provide successful symptom management and terminal care for young people, often in their homes.
19. Some nursing homes have successfully cared for young people with CJD through the terminal stages of illness.

Appendix 2. Contributors of written and oral evidence

Action 19+, c/o Campaigns Department, SCOPE.

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- Children's Trust, Tadworth: from Ann Gatford, Outreach Manager, including a compilation from several members of staff.
- Claire House Children's Hospice, Wirral: from Muriel Barber, Head Nurse.
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Watson, Eunice, Parent

Wells, Jeanette, Parent

West Kent Diana Community Children's Nursing Team:
from Annette Robertson, Team Leader.

Whelan Dr Jeremy, Consultant Medical Oncologist,
London Bone and Soft Tissue Tumour Service.

Whitefields Schools and Centre and Family Support Centre:
from Diana M Pitts.

Whittle, Maggie, Senior Lecturer, University of the West of England,
Faculty of Health and Social Care.

Whyte, Fiona, Macmillan Lecturer, Nursing and Midwifery Studies,
University of Glasgow.

Windebank Dr. Kevin, Consultant. Paediatric Oncologist,
Sir James Spence Institute of Child Health, Newcastle upon Tyne.

Wisbeach, Ali, Occupational Therapist, London.

Wraith Dr. E, Director, Willink Biochemical Genetics Unit, RMCH.

Young Adult Cancer Support Group, Leeds.

Appendix 3. Organisations and individuals who responded to consultation

Acorns Children's Hospice: from Dr Liz Ward,
Head of Education and Training.

Action for Sick Children: from Cheryl Hooper, Director.

Addington-Hall, Dr Julia, Senior Lecturer,
Department of Palliative Care and Policy, King's College London.

Barnardo's: from Alan Coombe, Principal Policy and Practice Officer.

Bewley, Jo, Wheatfields Hospice, Sue Ryder Care.

Burr, Sue, Paediatric Nurse Adviser, Royal College of Nursing.

Byrne, Dr Anthony, Acting Medical Director,
Marie Curie Centre, Penarth.

Caulfield, Helen, Solicitor, Royal College of Nursing.

Charles-Edwards, Imelda, Member, Royal College of Nursing.

Childhood Cancer Research Group: from Charles Stiller

CLIC: from Professor Gillian Mann.

College of Occupational Therapists:
from Gwilym Wyn Roberts, Group Head, Education and Practice.

Community and District Nursing Association: from Heather Ballard.

Contact a Family: from Linda Partridge,
Senior Development Officer (Rare Conditions).

Field, Professor David.

Independent Hospice Representative Committee:
from Anne Craft, Chairman,.

Jones, Sue, Team Leader, Coventry and Warwickshire
Diana Princess of Wales Team.

King, David, Principal Care Manager, Assessment and Fieldwork
Services, Northampton County Council and also Phoenix Lodge.

Lifetime Service, Bath: from Mary Lewis,
Senior Community Children's Nurse.

Marie Curie Cancer Care, Caring Services Division.

Murgatroyd, John D.

Muscular Dystrophy Campaign:
from Anthony M Lee, Executive Director.

National Association of Paediatric Occupational Therapists:
from Felicity McElderry, Professional Adviser.

Neal, Dr M A., Clinical Director, Wigan and Leigh Hospice.

Royal College of General Practitioners:
from Dr Maureen Baker, Honorary Secretary of Council.

Royal College of Nursing Paediatric Oncology Nursing Forum:
from Rachel Hollis, Chair.

Royal College of Nursing, Nurses Managing Hospices and SPC Services.

Royal College of Nursing, Paediatric Oncology Outreach Nursing Group:
from Pippa Chesterfield, Chair.

Royal College of Nursing, Paediatric Palliative Care Special Interest
Group, from Sue Wates, Chair.

Royal College of Nursing, Palliative Nursing Group.

Royal College of Paediatrics and Child Health: from Dr Tom Hutchison,
Consultant Community Paediatrician and Convenor of the British
Association for Community Child Health (BACCH).

Saunders, Dame Cicely.

Smallman, Suzan, Professional Officer Paediatrics, UKCC.

Smith, Sue, Senior Social Worker, Wakefield Hospice

Stevenson, Margaret,
Scottish Partnership Agency for Palliative and Cancer Care.

Tak Tent Cancer Support Group, Scotland: from Carol A Horne, Manager.

Tebbit, Peter, National Council for Hospice and
Specialist Palliative Care Services

Teenage Cancer Trust: from Simon Davies, Chief Executive Officer.

TOPS: from Polly Carr, Co-ordinator.

United Kingdom Children's Cancer Study Group (UKCCSG):
from Dr Sue Ablett, Administrator.

Whiting, Mark, RCN Community Children's Nursing Forum.

Wilkinson, Dr Susie, Head of Caring Services Research, Marie Curie
Palliative Care Research and Development Unit, Royal Free Hospital
and University College Medical School, London.

"She wasn't meant to be 19.
No-one knows what to do with her"