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Gillian Chowns BA, MSc, PhD, CQSW

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‘Until it ends, you never know...’: Attending to the voice of adolescents who are facing the likely death of a parent



Gillian Chowns

BA MSc PhD CQSW

Visiting Fellow, University of Southampton, Co-director, Palliative Care Works

gpatgc@aol.com

Abstract: In contrast to much adult-focused and adult-controlled research on the impact of cancer on families, the author’s action research project privileges the voice of young people whose parents were seriously ill. Its key findings, as demonstrated in the DVD they produced, were that the young people:

- Struggled with the sense of isolation and all-pervasive uncertainty inherent in the life-threatening illness of a parent.
- Preferred support and understanding to protection and prevarication.
- Disliked delay and deception, preferring to be informed and involved.
- Wished to be told the truth as fully and as soon as possible.

This article focusses particularly on the teenagers in the research group and presents their voices and views unmediated by adult exegesis. The author argues, on the basis of their evidence, that a clearer recognition of the capacities and competences of young people is needed by all who wish to engage with and support those facing the likely death of a parent.

Key words: Young people; serious illness; communication; death and dying; collaborative inquiry

All research is constrained and conditioned by time and place, and any research into children’s experiences must consider the contexts in which it is located. Childhood, (Holland 2005, Ribbens McCarthy 2006) as a relatively modern concept, was for many centuries but a brief interlude between birth and productive and re-productive activity, with most children required to contribute their labour to the family before their teens (itself a notion not in existence until the 20th century) and many moving into parenthood shortly after puberty. It was perhaps only in the nineteenth century, as formal education became established, that childhood became a distinct concept. Even then, children were clearly regarded as chattels, the private possessions of parents who were free to treat them as they chose. Rabelais’ assertion that a child was ‘not a vase to be filled, but a fuse to be lit’ was a rare dissenting voice and the concept of the State having some

responsibility for children, and of children having some rights independent of or equal to those of their parents, is relatively recent (Cunningham 2005).

In the last century the law steadily revised the age at which it recognised children’s right to an opinion, but in reality the first half did no more than mirror the prevailing medical practice of paternalism – a genuine and well-founded concern for others, but based on the assumption that the expert knew best.

Later decades witnessed a rapidly evolving social climate, to which the social construction of childhood was not immune. The right of children to have a say about their own lives was widely proclaimed, sometimes disputed, but gradually accepted by policy makers at least; the UN Convention of the Rights of the Child (1989) encapsulated this change in its assertion not only of fundamental rights to receive such things as education and shelter, but equally

importantly, the child's right to **contribute** their views and opinions on matters affecting them. Article 13 states categorically that 'The child shall have the right to freedom of expression ... to impart information and ideas...' and Article 12 elaborates this, highlighting the responsibility of 'state parties' to 'assure the right of the child, who is capable of forming his or her own views, to express those views freely in all matters affecting her or him'.

In the UK this was perhaps most clearly acknowledged in the Children Act (HMSO 2004) which gave the new Children's Commissioner the task of examining how well government and public bodies listen to young people.

The risk, however, of a significant gap between policy and practice is always present, and it can be argued that more recent models of childhood have not succeeded in replacing some of the older, influential constructions. Children are no longer regarded as possessions of their parents, but that possessiveness has sometimes been transmuted into the paternalism of the State, as evinced by the protectionist model, popular in the social welfare discourse, which remains influential. In health care, the accepted model of childhood was a developmental and default model; children were largely defined by what they were not – not adult, not competent, not physically mature. The dominant factor was biology, and this underpinned the assumptions of childhood as a process towards maturation, incomplete rather than rich and valuable in itself. Both this developmental model and the protectionist model framed children as inherently vulnerable and unreliable, and tended to the view that it was ethically unacceptable to subject them to interview when other, presumably more robust, individuals of integrity, such as parents, teachers and doctors were available to speak on their behalf. Thus, much of the research on the impact of cancer on families failed to engage young people directly (Ferrel *et al* 2002, Heiney *et al* 1997, Lewis 2004) preferring to accept the views of parents as to what they thought their children felt, rather than interviewing the children directly.

Research project

Existing research into the impact of cancer on families rarely captured the children's experience from their own standpoint; as a practising social worker in a palliative care team, supporting the children of seriously ill parents, I wished to adopt a more egalitarian and respectful methodology to research their experience and therefore chose a collaborative inquiry. Together with three adult colleagues, I gathered together a group of nine young people, ranging in age from seven to 15 to research their own lived experiences through the mechanism of making a DVD. Any theorising about frameworks or concepts would grow out of a fuller understanding of this experience, rather than be grafted on to an assumed knowledge of someone else's

experience, or constrained by established theories, whether of childhood, adolescence, development or empowerment. The intention was to give a voice to the children rather than to seek corroboration of adult beliefs and assumptions.

Such an exploratory, descriptive and emic inquiry does not claim objectivity; indeed it challenges the notion that objectivity is either desirable or feasible. Instead it endorses an approach that is involved, engaged and proactive; it embraces subjectivity, within a framework of disciplined and rigorous reflection and recognises that it presents a truth, rather than **the** truth. It seeks to understand contexts, diversity, nuance and process; it works with the 'epistemologically modest concepts of perspective and difference' (Mason 2002 p 16) rather than grand claims of universal realities.

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The children identified the themes to discuss, examined them through debate, interviews, games and reflection and planned and executed the filming.

Analysing a wide range of data sources – videotape, reflective diary, products of the filming sessions (flip-charts, post-its, mindmaps, feedback sheets, posters etc) brought its own challenges. While the goal was enhanced understanding rather than confident prediction, analysis was nevertheless a complex process, rigorous but inferential, organised but intuitive (Polit and Hungler 1999) – a process in which crystallisation and creativity were as important as categorisation and coding. Reason has argued that action research is in some senses a work of art (Reason and Bradbury 2008) and that held true for the analytical process. Any analysis is a creation, in that it is a particular, individual construction; it reduces, expands and extrapolates from the data to construct theories, concepts, or sets of findings. My aim was to stay open to possibilities for as long as practicable, rather than to arm myself with a fixed template, and my approach therefore closely paralleled that identified in Crabtree and Miller (1999 p 23) as the immersion/crystallisation method in which the researcher's 'prolonged immersion into and experience of the **text** (my emphasis)... and concerned reflection' enables one to emerge with 'an intuitive crystallisation of the data'. In this approach, the organising, connecting and editing aspects of the analysis are collapsed into one, or more accurately overlap, merge and separate over a time period that precedes the fieldwork and continues up to and into the writing phase.

Thus it was that the themes and codes began to *emerge* during this extended, reflective and iterative interrogation of the material.

It is important to acknowledge that my analysis and findings (Chowns 2006, 2009) represent a particular, and second-order framing of the young people's experience; the first-order framing is the DVD '*No-You Don't Know How We Feel*' (Chowns 2007). They selected and rejected footage; the video is their 'analysis' of their family experiences. In line with Masson's comment above, it does not therefore claim universality; age, gender balance, personality and family background all exert an influence. In an action research project, working with the lived reality of individuals, gathering together a group of young people was of necessity about working in a particular geographical area at a particular time with particular children, whose parents were seriously ill, who were able and willing to participate. The DVD is their framing of their experiences; how much is transferable to other young people will vary to an extent.

While many of the findings apply throughout the age range in the group (seven to 15), in this article I focus particularly on the evidence of the four teenagers, Ellis, Gemma, Natalie and Megan, and one almost-teen, Laura C. Adolescence is commonly recognised as a challenging time – for both the adolescents and their parents – and facing potential bereavement in the family inevitably compounds this.

Emerging Themes

Isolation

While all our co-researchers expressed a sense of isolation, the teenagers were able to articulate it most clearly.

Laura D: 'You're stuck in your own world, there's no-one to turn to... it's hard being by yourself.'

On occasion, isolation – as in alone-ness – had a temporary attraction, but was then implicitly rejected:

Laura C: 'You want to hide away, but you want someone to find you.'

As part of the project, all the children participated enthusiastically in an artwork session; their paintings were graphic, powerful and triggered some passionate but thoughtful exposition of their meaning.

Natalie, aged 14, chose sadness as her dominant feeling; her painting showed a solitary pale blue tear drop and she spoke of her sense of isolation.

The assumption that siblings might reduce the sense of isolation did not command universal support. Megan, aged 14, had two sisters, Laura D and Rachael. When Laura D

claimed that 'Having sisters is a good thing because you can talk to them' it drew the following emphatic response;

Rachael: 'I disagree TOTALLY. She doesn't talk to none of us.'

Megan: 'She doesn't talk to anybody.'

A consequence of this was that siblings did not always share knowledge with each other. Becky and Jack's Mum died just a few days before the last project session during which it became apparent that Megan was unaware of how ill she had been, whereas her siblings Rachael and Laura D were much better informed. Since Megan attended a different school from the one at which Becky, Rachael and Laura D were pupils, this may suggest that awareness of the parental illness was contained within the school setting and did not cross the boundary into the home setting.

However, to have no siblings at all simply reinforced the sense of isolation already identified earlier.

Laura C: 'You need someone to talk to. I'm an only child, no brothers or sisters...'

The fact that Laura C wanted to tell her Dad, who lived separately, about her Mum's illness, but was forbidden to do so by her mother, added greatly to her sense of isolation.

Uncertainty

As Christ (2000) acknowledged, the period pre-dating an anticipated death is usually more stressful than that after the death. The teenagers in our project testified to the difficulty of living with uncertainty.

For Ellis, aged 15, the frustration of 'not knowing if my Mum will get better' was all-pervasive, and this was echoed by Gemma and her twin sister Natalie (aged 14)

Gemma: 'I didn't exactly expect him to get better, but I hoped he would.'

Gemma identified one emotion only, '**confusion**', in her painting, which was a mind-map of unanswered questions such as '*What will happen to me?*', '*Will I get it?*', '*How can I help?*', '*What caused it?*'. She spoke of the overwhelming sense of uncertainty that she faced, concluding that

'until it ends you just don't know...'

In response to Laura C's question as to why she felt confused, Gemma explained: '*I haven't been in this situation before, I've no experience*'.

Living with the uncertainty of whether or when the cancer would return increased this sense of helplessness; cancer, even when treated, was characterised as a ghost that continued to haunt their waking moments.

Laura C: 'It kind of scares you, knowing it could come back... scary...you want it to go away.'

Support versus protection

Although there were times in the making of the DVD when opinions varied widely, there was great consistency concerning the need for support in facing the difficulties ahead rather than protection from them.

Laura C, the almost-teen, spoke graphically of the impact of her mother's cancer:

'When cancer clogs your life...your brain capacity gets clogged with pollution.'

Unarticulated but implicit is the need for some support, and all the teenagers spoke of how much they valued the collaborative inquiry group, not only for its declared research purpose, but also because of its therapeutic aspects.

Megan: 'This project's very good...we're making new friends, talking to people going through the same situation...brilliant... having someone to talk to.'

Laura C echoed this:

'It's easy to talk about it here, 'cos we're all going through round about the same thing'.

Another ways of giving support was suggested by Megan:

'We need a kids' Day Centre... a punch bag... a pillow.., a room for yourself, a room full of punchbags. Counsellors. And music.'

Equally important, however, was the unobtrusive support exemplified by the concept of 'space'. Understanding someone's need for space was crucial. Advice to teachers, parents and friends was often about giving space, with an implicit sense that the adolescents often felt crowded, pressured and directed, when what they wanted was freedom, distance and choice.

Gemma: 'We need space – if we've had an emotional evening, feeling down, then give us some space ... give us five or ten minutes outside, or to sit at the back of the class, or send friends to talk...'

Support was also desired from within the family, and was mourned when it was unavailable. As noted by a number of writers (Sheldon 1997, Chowns 2005) young people are quick to notice changes in their parents' behaviour, and the co-researchers gave several examples of this. Gemma and Natalie noted that while their father was, paradoxically,

more often 'there' because he was off work and at home, he was simultaneously less 'there' because he could not give them either practical or moral support:

'[Because of the chemotherapy, he's] drowsy.... falls asleep...he can't help with homework...not being there for you'.

One consequence of this was that the young people took on more responsibility and became more independent. For some of them, this 'empowerment' was experienced as positive; others were ambivalent. Natalie and Gemma recognised both advantages and disadvantages in it:

Twins, completing each other's sentences: 'You have to do things your Mum and Dad can't do. Dad's slow, he can't do much so we get impatient, then it's easier to do it ourselves. A pressure on us to be independent'.

Gemma commented that: 'it makes you more independent. You can't rely on both parents, you rely on yourself and the other parent'.

But Natalie qualified this: 'That's positive – that you're more independent – it's good when you're older, but not now...'

For others, increased responsibility was both practical:

Ellis: I had to do it all...do the cooking – dodgy!'

and emotional – feeling an increased responsibility for siblings. What emerged from the data was an important, though sometimes indirectly implied notion of reciprocity in family relations. This is often missing from the palliative care literature, but this sense of both children and parents reciprocating care and concern emerged clearly. They willingly accepted a responsibility as a family member to give as well as to take. Thus several of the youngsters demonstrated a protectiveness towards or sense of responsibility for their parents:

Natalie: 'you try to do the best...(if) you put pressure on them...that's bad'.

and

Laura C: 'I wanted to tell my Mum that I didn't like what was happening, but I didn't want to upset her'.

Gemma: 'When we're round our Dad, it's hard to forget, 'cos he does things a lot slower. You have to put up with it'.

Many of them therefore tried not to irritate their parents, aware that stress was not helpful, and so tried to shield

them from their own distress. This endeavour to give, rather than receive, support, conflicted with the adolescents' need for information, which I discuss later.

Friends were also a potential source of support, but there was less consensus from the teenagers on this. Ellis, aged 15, was positive:

'My friends know what I'm going through...I do tell them a lot. If they ask, I'll answer.'

Megan, while drawing enormous support from Laura C, a co-researcher who attended the same school and was a close friend, found friends who did not have a sick parent much more problematic;

'Mates are really nice – but also annoying. They say, "Everything's OK" and "we know how you feel". NO, they don't.

They say things, and if you're having a bad day it winds you up.'

Support in the school context

Laura C: 'School is not the best place to be.'

This topic generated some of the strongest feelings and substantial data. Although it is often suggested that the school may be a more peaceful, consistent and supportive setting than the home, the data from the project belies this, suggesting that it was often a source of stress. The two main sources of stress identified by the young people were homework and teachers, the latter because their assumptions, values and behaviours challenged both the children's construction of themselves as competent and their desire to be in control.

Homework was a significant problem, as Megan's sister, Rachael, explained.

'Homework, it's really hard to...once you've found out (about your parent's cancer) it's so hard to concentrate. You have loads on your mind.'

A consequence of this was that homework might be either done late, or badly, or both. What was wanted was a supportive response;

Ellis: '...Be understanding if homework happens to be late.'
Megan: 'Or crap'.

The implication was that teachers assumed that poor or missing homework was indicative of idleness and incompetence, whereas the co-researchers wanted their teachers to credit them with maturity and competence – and understanding as to why, on that occasion, they did not appear to manage this.

Teachers had a mixed press, with strong views on both sides. The major criticism levelled at teachers concerned their insincerity and their naive assumption that they could 'know' the young people's experience. This assumption that the adults, who had not had the same experience as the children, could know exactly how they felt was, without exception, deeply resented.

Ellis: 'Teachers say "We know your pain". No, you don't! You haven't got a clue!'

Rachael, not yet twelve, expressed her criticisms forcefully:

'If they know (about the illness) it goes in through one ear and out the other and that's what they say, "yeah, yeah", and they look out at space and they tell **you** to listen and then **they** don't listen, none of the teachers listen. They teach us not to listen, none listen – except one.'

The failure to listen and give genuine support was one source of irritation, but the hypocrisy of claiming to be one thing and doing the opposite was equally annoying. Implicit in this was an expectation of standards of behaviour superior to that ascribed to children, and an ability to look beyond the immediate for a deeper meaning. Thus Laura C, describing a scenario where a child might have had an argument at home with a parent and therefore not be concentrating at school, felt that a resulting detention would be unfair, since '*it is not your fault, 'cos you're feeling guilty about the argument*'. The implication was that the teacher should look behind the behaviour for an explanation of it that would take account of the home situation.

Those who were sometimes critical of teachers were nevertheless able to give appreciation where due.

When Jack asked why teachers asked so many questions, it triggered a lively debate.

Laura C: 'I think they care, they're trying to get involved.'

Rachael: 'They don't really care.'

Megan: 'They do, they care too much.'

Several of the group singled out particular teachers. Laura C and Megan, who had both been critical of unthinking teachers, had positive comments to offer, with Laura asserting:

'One of my teachers had breast cancer at sixteen, so she kind of knows how I feel... So that helps.'

Megan's experience was that

'My Head and Head of Year are helpful, I talk to them.'

Overall, advice for teachers was direct and critical – and sometimes conflicting. All the children wanted genuineness and understanding – as they had wished from their parents – and to feel supported. However, what was construed as supportive was variable and sometimes conflicting – as it had been in relation to their parents. For some, being left alone or given space was helpful, while for others, talking and being heard was supportive. Thus Megan's comments, while superficially contradictory, are in fact an expression of the *nature* of the support she would like.

'Just leave us alone, go easy' – but later, 'Be more supportive'.

Information and involvement in preference to delay and deception

All the co-researchers had a parent receiving palliative care. Despite, or perhaps because of their awareness of cancer's destructive power, all the teenagers actively sought more information about it:

Ellis: 'It's good to know what's actually happening'... 'just knowing more about it, treatment, chemotherapy'.

Natalie endorsed this view;

'Parents (should) try and make us understand, by explaining about cancer.'

And Megan was even more emphatic

'Tell your kids everything that's going on – or they'll not know nothing'.

All the co-researchers wanted their parents to give them as much information as possible, as early as possible. Regardless of what other supportive relationships might be available, parents were the preferred source for all the children.

Megan: 'Parents don't want you to be upset – but you still need to know.'

The implicit lack of confidence in parental honesty was nevertheless tempered by understanding. The young people were able to reflect on why their parents' behaviour sometimes fell short, ascribe reasons for it, and make allowances (intellectually) for it.

Natalie and Gemma: 'Why didn't she [mother] tell us? She didn't want to upset us...not sure herself, hoped he'd get better and she wouldn't have to tell us.'

This supports the findings in Barnes' paper (2000) that parents delayed communicating honestly with children in the hope that recovery from cancer would be possible.

Nevertheless, the twins were clear that this did not justify the behaviour, and saw it as bringing more complications, marginalising them as 'not-knowing' family members who were perhaps less competent or important than other 'knowing' members. It also undermined trust in the parent and contributed to the uncertainty and insecurity that seemed to be endemic in the experience of cancer. Their sense of agency was undermined also – as Gemma pointed out, without information, it was more difficult to actively support their parent:

'You need information... it's quite important to understand their point of view – so you can be patient with them.'

Telling the truth

As Jane Austen might well have remarked, 'it is a truth universally acknowledged' that, in palliative care, truthfulness is essential. However, our co-researchers' experience indicated that adults found this principle difficult to apply to young people. This was deeply resented by all the co-researchers, whether teenagers or younger, and they were unequivocal in expressing this.

Every member wanted not just the truth, but the whole truth.

Twins: 'Tell us the truth, tell us everything. Don't hide it, it makes it worse, freaks you up. Tell us exactly what's going on.'

Knowing the truth was not easy but was clearly preferable to being kept in the dark: as Megan's comments implied, forewarned is forearmed.

'Tell your kids everything that's going on or they'll not know nothing. Supposing you go into hospital – then they'll not know nothing.'

Ellis summed up much of this discussion succinctly:

'Children should be told what they want to know. They should be told the truth and nothing but the truth.'

Interestingly, Gemma and Natalie, the twins, qualified their initial statement somewhat, by suggesting that what they wanted for themselves, as adolescents, might not apply to all young people. They suggested that age was a significant factor in whether and when children should be told the whole truth;

'If you tell them too much, they might get too worried, too confused...it's OK for our age (14) but maybe under 10...?'

'It's harder, 'cos they don't understand the complications, to take all the information in....Just tell them the basics.'

This view was robustly challenged and then modified by the other co-researchers, as the discussion below reveals.

Co-researcher 1: 'Children should be told the truth – yes, definitely...'

'the truth should be told – but maybe gradually, over a longer period – not all at once'

Adult: 'At what age? Any age?'

Co-researchers (several): Yes, any age.'

Adult: 'It doesn't matter what age?'

Co-researcher 2: 'No.(it doesn't matter) If you don't tell it, they may not understand, they get the wrong idea.'

There was a general consensus – which contradicted some of the comments about withholding information from younger children – about the timeliness of telling. Everyone wanted to be told immediately, and cordially disliked delay and secrecy.

Megan's younger sister Rachael made a powerful point;

'If you're told late, you just feel you've done something wrong.'

And Laura C's tone of voice betrayed the anger she felt:

'Mum was diagnosed on my birthday – she didn't tell me til the Saturday.'

When family life is changing, a parent is clearly deteriorating physically, emotions are volatile, but the truth is withheld, it is unsurprising that the adolescents begin to doubt their parents. As one of the twins said:

'After a while we did get suspicious.'

Although the young people's preference was for parents to initiate the conversation, several of the group made clear that there was an option for them to take the initiative themselves, exercising power by challenging parental power.

Laura C: 'They just want to do the best for you, so they don't tell you – so you can just ask. You don't have to sit there.'

Natalie and Gemma: 'She didn't tell us exactly.. She said, 'Don't worry, it's not serious, he'll get better'.

'Mum, it's more serious, he's getting worse, tell us.'

Foretelling

Finally, telling, in the sense of talking about dying, was also acknowledged as risky for some of the group, because it might become foretelling. That is, saying out loud, or talking about whether someone might die, might 'make it happen'.

Laura D: 'If you talk about dying, it might come true.'

Laura C: 'Why?'

Rachael: 'I was speaking about it to my Mum and it did come true.'

However, Ellis disagreed with the premise entirely:

Adult: 'Does talking about it make it come true?'

Ellis: 'No!'

Discussion

It is clear from this research project that the young people, as offspring of parents with cancer, lived with both contradictions and uncertainty, negotiating their way through systems whose assumptions of their (in)competence and (vulner)ability did not match their own aspirations or self-perception.

The data revealed that all the children – but particularly the adolescents – exercised considerable agency and empowerment, albeit unevenly and sometimes unsuccessfully. A key finding was that the children demonstrated sophisticated communication strategies, distinguishing between talking, telling and foretelling, and making careful choices as to when and with whom to talk. Also significant was the importance of experiencing a safe place within which it was possible to both contain and release the strong emotions generated by the experience of living with a seriously ill parent.

This lived experience made negotiations around family life complex and shifting. The children's desire to be seen as competent frequently conflicted with their experience of society – and parents – as deniers of competence. There was a unanimous desire from children that their parents should tell them the whole truth as early as possible – and also, a mature understanding of how and why parents failed to meet this need for openness and honesty. Nevertheless, they were clear that this did not justify the parental failure.

St Exupery comments that '*grown-ups on their own can't understand the world from the child's point of view, so they need children to explain it to them*' (2002 p 6). This recognises children as the experts on their own world and competent to be guides or translators for inexperienced adults. While this view has been strongly criticised in some quarters, our collaborative inquiry group used the DVD

to 'explain' the experience of living with serious parental illness to the adult world, and in so doing, demonstrated a level of maturity and competence that adults are often reluctant to recognise. However, as Alderson (1995) noted, competence may be quite different from either intelligence, as measured by reading or maths ability, or compliance, and may well be fostered by adversity.

Conclusion

This article has highlighted some key issues that emerged from the research project, and which are clearly articulated in the resulting DVD (Chowns 2007). However, the overarching, and equally significant, evidence from the project is that children and young people are more capable and articulate than most adults give them credit for. It is not protection that our co-researchers asked for, but understanding and respect. They wanted their coping strategies to be acknowledged and respected. They wanted to be included and involved, as persons in their own right, not ignored and marginalised as 'not-yet' people who were too vulnerable. They wished to be counted, not as potential workers of the future or consumers of palliative care services and goods, but as supportive family members and as change agents and givers of knowledge to other families. While vulnerable to all the emotions and imperfections of children (and adults), they saw themselves not as passive victims but as active contributors to the good of others in the family.

Young people whose parents are seriously ill present particular challenges. Their status in society is disputed; their competence and understanding undervalued. Their rights and needs are often in conflict with those of their parents. Their future is uncertain, for they do not know when they will join the ranks of the bereaved. Yet, effective work with these children rests on a few, well-known, simple precepts. Our role is not to become part of the problem by increasing their dependence on us, but rather genuinely to empower them to find their own way.

The lesson for palliative care practitioners is clear; if we genuinely wish to offer sensitive, appropriate support to young people, we need to critically examine our taken-for-granted assumptions about childhood and vulnerability and move towards a better understanding of children in contemporary society – one that acknowledges not only the needs of young people but also their capacity and competence to deal with the challenges of living with serious illness and anticipated parental death. ■

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