MAKING USE OF HINDSIGHT
SUMMARY REPORT

This short report discusses the findings of a UK survey of parents whose children took their own lives. The research was a collaboration between **PAPYRUS,** a voluntary organisation which aims to prevent suicide among young people, and the University of Hull. A total of 46 parents completed the survey. Their views provide a unique insight into suicide prevention and the impact of suicide on families. The survey findings are summarised below and these are followed by a discussion of each theme.

KEY FINDINGS

- The warning signs of suicide are difficult to detect. Much of what parents now thought might have been indicative of suicidal intention remained difficult to distinguish from ordinary teenage behaviour, even with the benefit of hindsight.

- Parents advised other parents to keep channels of communication open with their children. This requires effort and patience; a non-judgemental approach was advocated as most helpful.

- Parents need advice about the range of health services available. They advised other parents to persist and to be assertive in their search for expert help.

- Many parents experienced barriers to accessing professional support. A small number found themselves excluded by codes of confidentiality.

- Parents reported little public information about mental health problems or suicide prevention with young people. They suggested that education services could help develop and deliver information, as well as acting as a referral or advice point.

- Parents too need support. Those whose children are expressing suicidal thoughts need help from professionals. Those who have been bereaved need support - perhaps for long periods. Professionals require training on the most effective ways to work with such parents. Parents can also derive considerable support from each other.

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THE SURVEY

A confidential questionnaire was sent by PAPYRUS to its members and of these, 46 were returned (62% of these distributed (n=74). The responses were analysed by independent researchers from the Department of Social Work at the University of Hull who had prior experience of research into student mental health issues (Stanley et a] 1999). Only one parent reported for each family so there is no overlap between the cases reported. None of those who died was aged under 16 so in this report we use the term 'young people'.

Table 1 - Ages of Young People at Time *of* Death

Age	No. of young people
16-18 years	11
19-2 1 years	13
22-24 years	16
Over 25	6

The questionnaire explored a range of issues but was deliberately kept as brief as possible. Most questions were open-ended to allow parents to write about their own feelings and experiences. A small number of questions asked for information about the young people but these details were again brief and it is difficult to draw statistical inferences from them. Nonetheless, the 46 young people who died had similar characteristics to those included in national studies of suicide. The great majority (36=78%) were men Most were in the age group 19-24 at the time of their death (see Table 1). About half (22) of the young people were in full-time education at the time of their death, while 15 held employment and nine were unemployed. The questionnaire did not collect information on social class or ethnicity. The choice of method of death confirmed the national picture, with carbon monoxide poisoning and hanging being the most frequently reported (see Table 2). Young men were reported to have chosen more violent methods such as hanging or jumping. This again reflects national figures for male suicides (Appleby 2001).

Table 2 - Means *of* Death by Gender

Method	**Male**	**Female**
Carbon Monoxide Poisoning	10	3
Hanging	11	2
Fell/jumped from high place	6	-
Overdose of prescribed medication	3	1
Unspecified drug overdose	2	2
Jumped in front of train	2	-
Inhaled solvent gas	1	1
Drowning	-	1
Shooting	1	-
Total	36	10

A number of clear themes emerge from the parents' responses to the survey. These represent important messages for a variety of different groups - other parents, those involved in health and education services, those who work with young people generally and all those who wish to contribute to the prevention of suicide. This is a key part of the government's health strategy (Department of Health 1999) and the parents who responded to this survey have much to offer from their experience.

PARENTS' MESSAGES

The survey provided a range of information which parents thought other parents should know. With the benefit of hindsight, they were able to identify and reflect on issues arising from their own experience. Their most consistent message was that they advised other parents to take depression and any expression of ideas about suicide seriously.

Many now thought they had not realised the full extent or depth of the problems experienced by their son or daughter. One parent reflected:

> *I didn't realise that (his) seeming lack* of' *interest in the future was due to depression and that even small decisions caused him distress.*

For some this realisation prompted them to advise other parents to seek professional help. Others considered that all parents should be urged to communicate with their children about feelings by listening and talking.

The responses from parents also addressed the complex question of whether there are warning signs for suicide and if so whether parents can be alerted to

these. Twenty one (46%) parents did not feel that such signs had been evident at the time. Some now considered that they had missed signs or mistaken them for ordinary adolescent 'moodiness':

> *It's easy looking back, but the signs just seemed to fit with her age.*

When asked specifically about depression, nearly half the parents said they had not recognised such symptoms and had considered their child to be experiencing normal adolescence. Some parents had known that their child was depressed, but had considered this to be mild or felt they had been misled by signs of recovery or superficial normality.

Fourteen of the 46 parents (30%) had recognised cause for concern but had not interpreted this as warning of suicide. For those who were unable to point to any possible signs, the reasons for their child's death remain unclear. Support groups may have a particular role in bringing such parents into contact with others who have been bereaved.

A small group of five parents reported that their child had made one or a series of previous attempts to take their own life. The level of seriousness of these attempts was high. One parent reported nearly twenty attempts while another wrote:

> *son), as a young adult, made no secret his wish to die... (He) spoke often of suicide when he spoke at all.*

With the benefit of hindsight, 21 parents identified possible circumstances or signs that rnight have been relevant to their child's death. Social withdrawal was the most commonly identified sign (cited by 12 parents) but this ranged from a:

> *slight change in behaviour. Not wanting to discuss or plan ah ead*

to more extensive problems in relating to people:

> *great difficulty in mixing, going to school.*

Not all parents had considered social withdrawal to be a problem: it could be interpreted as a sign of growing independence.

Seven parents commented on their child developing sleep problems. Again the extent and type varied. One parent reported:

> *No sign at the time. In retrospect, he had seemed more tired than usual, but he had been leading a normal life. It seemed normal.*

Other signs identified by **parents in retrospect were** small in number. They included eating or appetite problems (3), self-harm (3), alcohol use (3) and illicit drugs (2). Again these parents called for more open or public discussion of suicide. A number of parents had undertaken reading on mental health problems among young people following their child's death. They had been surprised at the prevalence of such difficulties.

Each young person had a unique set of circumstances and characteristics. Their parents painted a picture of young people whose needs could be variable and hard to interpret. Attempts to summarise warning signs in a simple checklist format may therefore not be particularly helpful.

MAINTAINING COMMUNICATION

Parents advised other parents to keep channels of communication open with their children. They acknowledged that this might not be easy, particularly as twelve described their child as socially withdrawn. However, the key message for other parents was the need to communicate about feelings. This was seen as a way of uncovering problems and identifying their severity and possibly also contributing to preventing suicide. Half of the parents responding wished they had talked to their child more:

> *I wish I had picked up on some of the things he said and tried to discuss further.*

However they accepted that this could be difficult and intrusive and that forceful attempts could be counterproductive. Parents often linked the need for open communication with the importance of being non-judgemental and accessible.:

> **....** *keep lines of communication open at whatever level seems possible. Try not to be judgemental...*

Some saw this as an appropriate message for all parents of young people and considered that this should be promoted by public education.

Keeping the channels of communication open was also recommended by parents to other families coping with a child who was actively expressing the wish to harm him or herself. Even at these difficult times, parents advised other families to remain accessible and to listen to their child. One recommended:

> *Always be ready to talk and be there.*

SERVICE PROVISION AND PROBLEMS

One third of parents (16) wished they had been more insistent in attempting to get help from the health services. Being proactive and assertive was seen by some as important and they argued that parents should trust their own instincts.

Many parents felt they had not received appropriate professional help or advice. Some parents considered that young people's mental health should be awarded greater priority. Others reported specific criticisms of services, at times linking them to shortage of resources. Twenty (43%) identified deficits in the health service: particularly long waiting lists for appointments in the NHS, or in higher education institutions' counselling services. One parent stated:

> *son) went to the GP and was offered an appointment with a counsellor, which would have taken a few weeks to arrange.... I wish that (he) had the opportunity to speak to a counsellor sooner....*

The issue of waiting lists was brought up in another form by those parents who felt that young people's problems should be responded to more urgently. They considered that help for young people within the NHS should be 'fast track' and some suggested that young people should have a dedicated service.

Some parents also considered that there was a need for further referral or second opinions. These responses were also related to their child's assessment, care and treatment. In their view their child's problem merited attention from a specialist for assessment or treatment. One parent felt that lie or she bore some responsibility for not pressing for a further opinion:

> *With hindsight, we should have sought second opinions or treatment without being afraid of upsetting a psychiatrist.*

While some parents considered that services should have been called upon earlier, other parents voiced the opinion that it was not simple delay or inefficiency that were the problem, but that existing services did not offer the right kind of help for young people in general or their child in particular. One parent argued that the 'psychiatric' service should be replaced by community based provision for young people. Another had considered paying for an adolescent centre place in the private sector but the cost had been prohibitive. This parent argued:

> *(we) need a young people's mental health service with supportive residential accommodation and therapeutic input.*

In respect of their own needs, a smaller number of parents wished **that help or support had been available** to them when supporting their child. After the death of their child, some parents felt they had received insufficient or insensitive help.

Five parents considered they had received appropriate help and support. One wrote:

> *....our doctor made sure we knew he was there for us anytime.*

But this parent acknowledged that more support might have been helpful.

BARRIERS TO RECEIVING HELP

Twelve parents identified a lack of communication between health services and parents as contributing to difficulties in addressing the needs of young people. Seven parents argued that services should 'listen to' or 'include' parents more. Parents saw themselves as possessing important information about their children. One parent suggested that professionals need to be in touch with people who knew the 'background story'. Other parents considered that their perceptions would have been potentially helpful to services:

> *We, as a family, should have been included as we were living through this with him and could see how ill he was.*

Some parents described a failure of health services to provide both information and care. One parent reflected that:

> *.... we parents were not informed or advised what services could be available.*

This statement referred to the period following a serious suicide attempt when the young man was living at home with his parents. Another parent, who went to see her GP about her son's depression, said she was told:

> *....even if (my son) went to see him (the GP) there would probably be nothing he could do for him We were given the firm impression that no help was available. He (the GP) gave us no advice and made no suggestion that we might see someone else who might help....*

Problems over confidentiality and the young person's right to self-determination emerged when some parents sought to get help or information. A number of parents revealed their understanding of the need to achieve a balance between the rights of the young person to accept or reject help and their own needs and anxieties:

1 wish we had been more involved with (his) doctors, but he did not wish it... and we respected his right to be a free adult.

However, other parents struggled with the need to respect their adult child's wish for privacy and patient confidentiality was experienced as a barrier by some parents. One parent noted:

Because (my son) was adult, we were only peripherally involved.

Another reported that she had been told her adult daughter had a right to determine how much help her parents should provide:

The doctor insisted that it should he (her) choice.

RAISING AWARENESS

Parents considered how helping agencies and professionals could work to prevent suicide in young people. Their focus was on raising awareness and these responses can be divided into two main areas.

The first form of awareness raising identified was a health promotion approach aimed at the general public. Thirty-six parents (78%) thought that professionals should help raise awareness of suicide and mental health. Some (15) thought this should be promoted through the education system. Another fifteen thought that awareness raising should be directed towards the general population through the media One parent argued that there should be wider debate about young people's emotional and psychological needs with:

more discussion of depression and recognition of it being a different condition than just being 'fed up'.

Secondly, the respondents identified a need for specific advice to other parents who, like many of themselves in the past, were faced with a child having problems. For parents already aware of problems, the respondents suggested that advice could cover:

- more knowledge and awareness of mental health issues
- information about help from a variety of services
- details of a range of helping services
- how to be proactive in seeking help
- ways of remaining alert to changing problems.

SUPPORT FOR PARENTS

Parents identified a need for parents to seek support for themselves when struggling to care for a son or daughter who was distressed or experiencing problems. They provided a variety of suggestions about what worked for them. Eight commented on the value of accessing help from someone outside the immediate family:

Parents are probably too close to the child and their deep issues and may not be in the best position to help. Try to find someone else who can....

Eleven noted the importance of seeking support or advice for parents when a son or daughter was actively suicidal:

Parents need guidance from psychologist psych iatrists/counsellors themselves on how to best deal with the situation.

Six suggested that parents should not attempt to take total responsibility for their sons or daughters in such situations.

Parents' own needs after their child had taken their own life were also highlighted and this is one area where the experience of **PAPYRUS** members is uniquely valuable. A number of replies indicated that parents felt the reasons for their child's death remained unclear. Support groups may have a particular role in helping such parents. A legacy of self-blame and guilt was also evident in the regrets expressed by parents (see Table 3). Almost half wished they had talked to their child more. Some of these feelings of responsibility suggest that parents might benefit from support in carrying such emotions. Again, other parents could be uniquely helpful. One parent described a web of support, including her doctor and church and

the countless parents of `suicides' who wrote or phoned saved our sanity and our lives.

Thirteen parents now regretted that they had missed warnings signs. One said:

I wish I had the wisdom and insights to interpret more accurately the signals he gave out.

Table 3 - Parents' Regrets

Theme of response	No. of **respondents**
1 wished I'd talked to my child more	22
1 wish I'd been more forceful with health professionals	16
1 wish I'd read the signs	13
1 wish I'd spent more time with my child	9
1 wish I'd had time with my child at the end	7
1 wish I'd pressurised my child less about achievement	6

Nine others were saddened that they had not spent more time with their child whilst six expressed the view that they should not have placed such emphasis on academic achievement. These replies suggest that many parents carry a heavy burden of self-blame with a further seven wishing they had been there at the end or had 'made up' with their child before he or she died. This legacy of guilt and enduring feelings of loss suggest the need for appropriate and on-going support for parents.

CONCLUSIONS & RECOMMENDATIONS

Warning Signs

Warning signs are difficult for parents to detect and interpret, even in retrospect. They vary considerably. This indicates the need for general alertness and awareness rather than a checklist approach to identifying warning signs. Young people with a history of suicidal thoughts or actions should be taken seriously by professionals.

Family Communication

Parents recommended that talking to and listening to young people, especially about feelings, were important. They urged parents to keep channels of communication open.

Getting Help

Many parents experienced difficulties in accessing the right help at the right time. Some parents described a failure of health services to provide both information and care. They encountered barriers in that professionals did not recognise their role as parents or carers. Parents might benefit from advice about the systems of support for young people. Professionals and carers' groups need to explore ways of working together that support parents without disadvantaging the young person.

Developing Prevention

Parents saw educational services as useful channels for communicating information to young people and their parents. These could help educate the wider public about common problems and needs. Education services could also direct families to appropriate sources of help.

Supporting Parents

This survey suggests that parents whose child is actively expressing a wish to take their own life need particular support. Organisations such as PAPYRUS have much to offer professionals who work in this area. Together they could develop evidence about what is helpful and effective (see also Harvey, 2002). Secondly, those parents whose child has taken their own life often carry a heavy burden of self-blame, which may be compounded by events after the child's death. Professionals working in this area, including the Police, coroners, health services, education and religious organisations, may benefit from training on the most effective means of support. The impact of the death of a child in such circumstances may endure over many years and such support should not be seen as a one-off or single event.

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