Life and death issues

Ian Florance talks to **Christine Kalus** about working in palliative care

Christine Kalus describes giving evidence to a House of Lords Committee on the Assisted Dying for the Terminally Ill Bill as 'one of the most terrifying things I've ever done.' Hopefully, talking to me was slightly less nerve-wracking. She described her route into psychology as a mature student, and an approach to her work which is passionate, exploratory and hugely illuminating on what psychology can offer at a crucial point in people's lives.

There's a lot of guidance on the Society website about how to train as a psychologist; you seem to have made up your own training route!
I am not sure that is the case. However,

I recognise that teachers, academics, patients and others have been crucial to my development as a professional and as a person. I believe that as a clinician, particularly when one works within a particular humanist and phenomenological tradition of therapy, the personal and professional are intrinsically linked. Many of the people who have provided a positive (or negative) influence have given me the confidence and insight to believe that I have a contribution to make, and this continues to be the case.

I wasn't academic at school; I married young and went into full-time education when our daughter was five. In a sense we started school together! Prior to this my husband did a maths degree, which further inspired me to re-enter education.

Coming into education as a full-time student, and from within an established family life, brought its own challenges. I was initially turned down for both A-level and degree-level psychology because of my rather chequered academic background. However, I am a pretty tenacious person. Fortunately others, both tutors and personal friends (not to mention my long-suffering husband and family), were prepared to give me a chance, and once I was accepted onto the different courses, I had to apply a great deal of determination and hard work, none of which I have ever regretted.

What interested you about the area?
It is difficult to be specific about particular interests, although I first became fascinated with philosophical and theoretical ideas relating to human functioning after having been through an experience of personal therapy when I was in my late teens.

I am also committed to the concept of service to others. The deeper I became involved in the theory and practice of psychology, the more I realised that it was an area where I could further develop my understanding by helping others in a variety of domains, including clinical work, teaching and training, writing and research. I have been really fortunate to have had a career (so far at least) that has allowed this to happen.

How did your career in clinical psychology develop?
As an undergraduate I had the opportunity to work in a voluntary capacity within a clinical psychology department. This was formative because I got an insider's view of the work that many undergraduates – at least in the late 1970s – did not.

Following completion of my first degree I worked both as an occupational therapy assistant in a local mental health service, and then managed to obtain a post as a psychology technician (now known as a psychology assistant).

It was while I was in this post that I worked within older persons' mental health services, which did not initially fill me with pleasure. I had always thought I would want to work with children. However, after a few weeks in the post I was converted and spent many happy years, both prior to training and once qualified, working in such services.

Older people often have such an individual and interesting view of the world if we take the time to listen. Working with them and learning about managing transition and loss, often at the end of life, led me into my work in specialist palliative care. At the time there were probably fewer than a dozen of us nationally.

How did your post as Macmillan Consultant Clinical Psychologist at the Rowans Hospice come into being?

In the early 1990s I developed many links with local, national and international bereavement services, as well as within the NHS. My post within older persons' services developed in this direction, including offering training days on understanding bereavement and loss for people who were going to work as volunteers for the (still to be built) Portsmouth Hospice, The Rowans.

At the same time many of the key staff within the purchaser and provider arm of the NHS were involved in working with The Rowans Charity as it started to develop the new specialist palliative care service. They were convinced that charity and NHS clinicians had to work closely together with the aim of providing a seamless service for the people of Portsmouth and surrounding areas. I was asked if I would like to become a part of NHS component of the brand-new service, taking a particular responsibility for bereavement service development and provision. I jumped at the chance, and have not regretted it once since I started.

What are the key issues for you?

In my view, palliative and specialist palliative care is one of the last bastions of compassion within an increasingly outcomes-driven health system.

There are many positive and constructive psychological, social and biomedical interventions that we can offer people who are reaching the end of their lives, but there is no 'quick fix'. It can be very hard to be alongside individuals and families who are finding it difficult to accept the suffering that they experience. Many of us within the speciality are open with the patients and families about this. They may not like the facts of their situation, but often value our candour.

I believe that it is a huge privilege to be with people towards the end of their lives, to hear the stories they tell and the stories their friends and families use to memorialise them. These stories can influence or become part of our own stories: my personal values have been challenged and refined over the years.

When someone is reaching the end of their life they may not have a sense of a 'life well lived' and their sense of personal integrity (in Erikson's sense) may be so damaged that to work psychotherapeutically with them could be damaging – I view it as 'adding insight to injury'. We have to judge whether and how we offer them a service.

Much of my work relates to helping people manage suffering. Whether this is with individuals who are approaching the end of their life, or their relatives and friends, I believe that my job is to help people find a personal context for managing this, and if possible, help them to make sense of it. This is not always possible and, as I have said above, not always desirable.

As a clinical psychologist, I have training in understanding different models of human development, behaviour, emotional and cognitive functioning. This allows me to integrate these different models, and hopefully develop bespoke assessments, formulations and interventions that will best meet the needs of the patient, family and staff I am working with.

Do you think the 'science' part of psychology is in conflict with the 'spiritual' aspects of what you do?

That's a difficult one to give a brief answer to. There are conflicting views of science within psychology, and no doubt the world of science as a whole. Exploration of spirituality, religious belief, behaviour etc, will inevitably highlight many of these conflicts because of the contentious nature of the subject. Despite this, I am concerned that there is a tremendous arrogance within those clinicians and researchers who are reluctant to address the issues that are so fundamental to human functioning.

Personally, I don't believe that I could work with integrity as a clinician and not embrace the spiritual. Questions of existence are embedded within the therapeutic conversations I have with patients and families, and to ignore these, or refer them on to the Chaplain or other religious people, would be to deny the relationship that I am working within.

Why were you asked to give evidence to the House of Lords Select Committee on Assisted Dying?

The Special Interest Group of Psychologists working in Oncology and Palliative Care (SIGOPAC) is a national group and I have been the chair of the palliative care subgroup for the past few years. In this capacity I have been contacted by a variety of organisations to comment on the work that we do, and the research that supports this work.

I was approached by the Secretary to the Select Committee to offer evidence to the Committee on behalf of the BPS. At that time the BPS did not have a view, and so I had to go as an expert witness. My colleague Elaine McWilliams accompanied me and my husband, PA and Psychology Assistant also came along to hear the proceedings, and provide huge amounts of moral support both before and after the event!

I offered a prepared statement, which had been endorsed by the then Chair of the Division of Clinical Psychology, Professor Peter Kinderman, and Ana Padilla, the BPS Parliamentary Officer. The Committee was interested in the psychological issues related to requests to die when one has a life-limiting disease. The topics we addressed included mental health problems, depression and anxiety, mental capacity and an existential desire to end one's life because the individual deems it is not longer worth living.

And it has also led to other work?

Yes, I have been approached by the House of Commons about related issues, as there was considerable work going on last year on end-of-life care.

I also approached the BPS to consider the development of a working party to produce a document which would both introduce the reader to research into psychological aspects of end-of-life care and also highlight the work of psychologists within specialist palliative care. Fortunately, the BPS was responsive to my request and the report was published in May [see Society, p.610].

What does the future hold?

For me, who knows! I remain committed to the work and the speciality, and I hope to be able to develop training packages relating to communicating with dying and bereaved people, which would be an extension of some training videos I produced, in conjunction with the University of Portsmouth some years ago.

In addition to this, I believe that we need to get more newly qualified staff working within the speciality, and thus training clinical psychologists is key. We have a steady stream of trainees on placement at The Rowans Hospice.

We must also remember that there is room for all sorts of people in this area: clinicians, academics, people specialising in health and clinical psychology. We need more people who can apply psychology to this specific area. The focus has been on oncology until recent times. There are many other conditions – heart disease, Alzheimer's, AIDS-related illnesses – which contribute to peoples death. The profession needs to consider the generic and specific skills its graduates need to work within the general domain of end-of life-care and into bereavement.

How would you sum up what you get from your work?

In brief, it can be very sad; it can be extremely uplifting! I still cannot think about another area within which I would want to apply my skills.

Psychology Ltd

Jessica Eade on the challenges facing psychologists who decide to set up in private practice

Two days after finishing our doctorate courses in clinical psychology, along with Karen Kemish I started to create Kemish-Eade Psychology Ltd. It was launched in October 2007. Why did we take this route, and what issues might psychologist face when setting up in private practice?

The big decision

My primary motivation for taking this step was a lack of local jobs for applied psychologists. After years of hard work to qualify, Karen and I were determined to deliver a psychology service. As we both have young families, moving was not an option.

Different routes to the same destination

Although we have both worked in psychology-related roles for 10 years, we came to train in clinical psychology via quite different routes.

Karen initially ran her own ladies fashion shop. In a radical career move she took a post as a support worker for clients with schizophrenia. She wanted to understand more about complex mental health issues and studied psychology at Bangor University, graduating in 2002. She then joined the NHS as an assistant psychologist, predominantly working in adult mental health, pain management and chronic fatigue. She undertook doctoral training in clinical psychology at Bangor University in 2004.

By contrast, I was unsure of what I wanted to do when I first left school. Psychology looked like the most interesting course in the prospectus, so I also applied to Bangor! I graduated in 1997 and was fortunate to get a research post with Professor Mark Williams, under whose supervision I completed a PhD investigating the influence of dieting on affect and cognitive functioning. I then worked for 18 months researching the effectiveness of the Incredible Years Parenting Programme for school-age children with behavioural problems, before joining the same course as Karen in 2004.

A steep learning curve

Our joint practice interests lie in adult mental health. There are few other practitioners offering this type of service privately in our rural community. Add this to the demand for psychological therapies, and we assumed that demand plus supply equalled instant business. This proved to be a naive assumption: in the first three months we had a handful of enquiries and saw only one client!

This challenged us to consider public and professional perceptions of clinical psychology, as well as our own. We had both internalised the idea that as psychologists we should stay in the background, working inconspicuously. However, this perspective contradicted our vision of a fresh, accessible and dynamic practice. Once we had

Setting up in private practice

Here are some of the key issues that we had to face.

1. Practicalities – finding suitable premises; financing ourselves through the initial months, particularly as third party referrals often involve deferred payment and this can take up to 60 days; developing risk management procedures; all those small business requirements, like data protection; to be self-employed or limited? We relied heavily here on advice from the BPS, local business services, a good accountant, and clinical psychologists already in private practice.
2. Fees – deciding on what to charge and how to physically take the money was difficult. Rates vary enormously, dependent on a variety of factors, including services offered, who is paying, experience, gravitas, and geographical location. We take payment from self-referred clients at the end of each session and have installed a card machine, although, interestingly many of our clients still prefer to pay in cash.
3. Hats – we have had to adapt to wearing many hats: from therapist and business person to press officer, author, company director, cleaner, secretary, accountant, hostess, and so on...
4. Networking – as newly qualified psychologists we have had to work hard to establish links and to educate potential referrers and clients about our service. But in addition to networking for sales, we have also networked to raise our profile and simply for the joy of it – establishing links with the local university, offering to provide talks and mentoring undergraduates interested in a career in psychology.
5. Personal Support – it is important not to be isolated emotionally. We make sure that all our family, friends and previous colleagues know about what we are doing; it raises our profile but gives us a sense of team that we might otherwise miss if operating alone.
6. Marketing and advertising – striking the balance between sensitive advertising while demystifying our service and breaking down boundaries to accessing psychological help is difficult. Although advertorials in the local paper can create instant sales they are costly; mail shots and newsletters to potential referrers are cheaper, but it takes more time for work to filter through.
7. Supervision – accessing supervision from a one-stop shop has not been possible for us; we have had to be more flexible, sometimes even accessing a specific supervisor for a specific case.
8. CPD – expensive workshops can be avoided: there are ways of keeping a healthy CPD log by being creative and without breaking the bank. We found the BPS gives good advice on this matter.
9. Gravitas – we have been challenged by this aspect, but have had to remind ourselves that being newly qualified still means that you are trained to do the job with the same integrity as more experienced clinicians.
10. Keeping the passion – we have found it important to remind ourselves from time to time why we started on this adventure!

Jessica Eade and Karen Kemish

acknowledged this disparity we were able to solve our marketing problem. Instead of ordering the royal blue chairs for our group room we opted for the lime green ones and placed our first newspaper advertorial, Bringing Psychology to the High Street.

In raising awareness of mental health care provision in this way we feel that we are also helping to break down barriers and reduce stigma.

Where we are now

We have focused initially on developing a service direct to the public, relying on self-referrals and referral via GPs. We do this through newspaper articles, mail shots and a quarterly newsletter among other activities.

Since starting up we have seen clients with a variety of difficulties: anxiety and social phobia; depression; childhood trauma; invalidation leading to self-esteem and low confidence issues; relationship issues; grief; addiction; autism; anger; and obesity. We both work from a cognitive-behavioural perspective, but we also draw on mindfulness and compassion-focused techniques.

Many of our clients do not meet NHS criteria because they are perceived to have problems that fall into the mild-to-moderate category. Some of them have come through rehabilitation services and direct from solicitors following personal injury.

We aim to bring a psychology presence to other areas of working and in the process raise the profile of our practice. For example, Karen has just completed training to become a registered intermediary with the Office for Criminal Justice and Reform, where she will help vulnerable witnesses and victims to give evidence at investigation and trial.

Public needs can change, and we try to respond proactively. For example, in considering obesity, we have developed a group addressing the problem of emotional eating: applying psychological theory to understanding why people might over-eat. We just have to market it now!

Where we would like to be in the future

Other than 'on a beach in Honolulu', we would like to expand the business, be able to take home a reasonable wage, offer employment to assistants and continue to develop our range of services. Perhaps this is more of a rural issue, but we see a great deal of work to be done in breaking down barriers between us and other health professionals, private and public sector organisations.

We have had to deal with criticism that it is unethical to charge people for a service to which they should be entitled. The crux of the matter is that this service is not always readily available on the NHS. People are often given the option of where they would like to get their physical difficulties treated; what about their emotional well-being needs?

FEATURED JOB

Job Titles: Consultant Clinical Psychologist; Senior Clinical Psychologists; Clinical Psychologist
Employer: The Hesley Group

The Hesley Group provides residential care, education and vocational services to both children and adults, drawing its clients from across the UK. Fred Furniss, Consultant Clinical Psychologist at the Hesley Group, is precise about the core focus of range of jobs on offer.

'We work with young adults who have severe intellectual disabilities, display challenging behaviours and, in many cases have marked features of autism. We work with each service user to develop a life plan based on individual specific aspirations, needs and capabilities and support people in making their own decisions. We're looking for psychologists who are really interested in psychology and its applications in this field: people who know the theory and practice but can adapt general approaches to individual needs, find new ways of doing things, challenge existing methods and interventions to find better ones. We don't look for people with one therapeutic approach or framework, nor do we impose one. We look for a range of approaches because the issues we face are diverse and complex.'

> "we're as person-centred with our staff as we are with our clients"

'Achieving significant change can sometimes take time with our clients, so we're also looking for people who can support each other and our colleagues in speech and language therapy and psychiatry and make a real contribution to the clinical team. Much of our work is about making psychological understanding of the needs of our clients accessible to direct support workers and helping them to deliver psychologically minded care.'

Fred points out that the posts have very much the same focus and all involve some work with individuals. But he does make a distinction. 'The consultant must be able to work at multiple levels, national, service, unit and individual, and must be interested in service development, as we expect significant change in our services over the next five years. The Senior Clinical Psychologists are responsible for clinical psychology input at one of our services and will provide clinical leadership in those areas. We expect applicants for the post of Clinical Psychologist to be recently qualified and we will support them in formal post-qualification training.'

CPD, participating in conferences and networking events and research are all seen as important. 'We're not part of the NHS and we feel these areas are important for our staff so that they can develop and we can innovate and improve. But we're as person-centred with our staff as we are with our clients – we reflect their interests and aims.'

Fred sums up. 'Because we are so focused on individuals with complex needs, it's important that our psychologists either are, or become, self-directed. They must be able to take a long view of a client's progress and capable of contributing to decisions that really improve clients' lives.'

You can find this job on p.623, and on www.psychapp.co.uk, where you can also sign up for e-mail and RSS alerts