CONCLUSION

In this brief article, it has only been possible to outline some of the principles of the family systems approach and to describe in detail the actual methods used is beyond its scope. One of the main strengths of the approach is that it provides a way of engaging from a position of respect with the different ways that families have of surviving stress and trauma, but which may have become stuck in rigid or unhelpful patterns. This combined stance of respect and curiosity creates a secure base from which to help people move beyond their habitual interactional range and discover more creative ways of dealing with emotions and relationships. BC

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Further reading

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Walsh F, McGoldrick M. Living Beyond Loss: death in the family. New York, USA: WW Norton, 1991.

The family systems approach

For an introduction to this approach, either of the following can be recommended:

Burnham J. Family Therapy. London, UK: Tavistock Library of Social Work, 1986; or

Jones E. Family Systems Therapy (Family Psychology series). Chichester, UK: Wiley, 1993.

Training

For a list of training courses in the UK, contact the Asssociation for Family Therapy, Administrative Secretary, Chris Frederick, 12 Mabledon Close, Heald Green, Cheadle, Cheshire SK8 3DB

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Grief and isolation after an AIDS-related death



Marian O'Regan NNEB

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Tony and I met in Belfast and became firm friends over the next two years. Then came the full relationship and a growing commitment. Soon we were setting up home, living every moment and planning for our shared future. Each of us blossoming in the new-found love and trust, we intended getting married, maybe starting a family.

One year on, Tony became unwell. After two months he was admitted to hospital, both of us relieved that the underlying cause would be investigated. But within seven weeks he was dead, diagnosed HIV-positive three weeks earlier when already too ill for treatment.

That's the potted history. Whilst friends and family were reeling with the news, we moved rapidly from the phase of agonised struggle against unknown illness to an acceptance which allowed us increasing closeness in the accelerating nightmare. In some sense already out-of-step with others, we celebrated our wedding in hospital, an important step in completion for both of us. I was with Tony when he died, able to wash his body and then take the time I needed there, thanks to the hospice where we spent our final 24 hours. I was 37. Previously dedicated to my vocational work, this had been my only relationship, and Tony was my closest friend.

THE IMMEDIATE AFTERMATH

I was in shock: I went through everything that needed to be done with my usual attention to detail, but it all seemed unreal and nothing was automatic any more – not eating, sleeping, nor even breathing during waking hours. Support came from the local AIDS unit (although Tony had not been a patient there) and the undertaker they recommended, seeing my grief, offered me a lock of my husband's hair – a vital keepsake I'd never have thought of taking.

At first I stayed with friends and then my

EDITOR'S NOTE

Although the mortality rate from AIDS has halved in recent years, deaths do continue to occur and may indeed rise in frequency if the improvement produced by current methods of treatment does not last. Certainly AIDS causes manifold problems for those who suffer it, their families, their lovers and their friends. In this moving and insightful paper Marian O'Regan reports her own experience of bereavement by AIDS, having suffered the sad loss of her husband as a consequence of this disease. Her knowledge of care and counselling (she worked for 20 years in in child care and community work and has recently completed training in bereavement and abuse counselling) enabled her to make full use of the facilities available to her as well as to criticise them from the point of view of the 'consumer'. Her article complements the outline of the field by Shearer and McKusick in a previous issue of *Bereavement Care*[1]. For a more detailed treatment of this complex field, Klein's book, *Heavenly Hurts: Surviving AIDS-related Deaths and Losses*[2] is recommended.

1. Counselling the survivors of AIDS. *Bereavement Care* 1998; **7** (2): 21-22.
2. Klein SJ. New York, USA: Baywood, 1998.

mother came for several weeks, during which time I tried my best to behave as if life would be 'normal' again. When alone I couldn't stop crying. Aware there was worse to come, I encouraged her to return to Wales. With her, as with others, there was the stark realisation that, although I needed help more than ever before, I could no longer gratify anyone by letting them feel they'd 'made it all right'. Nobody could bring Tony back.

Survival and the AIDS factor

I had little or no idea of surviving, from the very start. I expected to be HIV-positive, and thought this would solve the problem of not wanting to go on alone. Even after repeated tests I was not convinced, especially as I was experiencing many of Tony's symptoms – nausea, diarrhoea, sweating, backache, skin irritations. One perceptive hospital counsellor, instead of reacting like everyone else with relief and delight, asked me whether I had wanted a positive test result which allowed me to share the truth and feel understood.

Neither Tony nor I had the slightest wish for secrecy, and in bereavement I continued the bias towards openness. Northern Ireland had a comparatively low incidence of HIV/AIDS at that time, and some were keen it should be hushed up. But my primary requirement from any friend or professional was an acceptance of both this and Tony's earlier history of homosexual relationships (from which time, longer than we'd deemed possible, he'd been carrying the virus). We were unusual in having only weeks to live with the knowledge of his condition, and how I wished for those extra years! In this respect I felt the odd one out in AIDS organisations, where I otherwise seemed most to belong.

A few months on, I applied to go on a weekend in England for people bereaved by AIDS. But it was cancelled and, with my only prospect of tailor-made help withdrawn, things now went from bad to worse. I was becoming less and less able to arrange and follow anything through. I felt all used up with no means of replenishment, my coping mechanisms exhausted during Tony's illness. I wished there were hospices for the bereaved, such was the intensity of care and involvement I needed. I had faced both expected and sudden deaths before, deriving from them an enhanced commitment to living; but this took my entire life along with it, getting only worse with time.

Increasingly isolated and suicidal

I just could not fathom this forever loss. My mind went ceaselessly over the final weeks, which others found too painful to dwell on. However, the content of the rest of our time together largely disappeared, an abysmally cruel twist; I could not relate even to the photographs, except those taken in hospital, though I clung to them as proof. Physically and sexually my body remembered, and the grief was intensely physical. Dimly I understood that to remember and take in all I'd lost in one go would have driven me to instant suicide.

The only way I regained any sense of myself was in telling the story, reaching for the memories. If people avoided or discouraged this, I felt they were causing – or at least colluding with – my mind's blocking. Not only had Tony vanished from the planet, but I felt as if my skin had been ripped off: hurt after hurt followed.

AIDS is killing me
stealthy virus that sapped your strength
has stolen my life
by destroying hope and happiness

HIV has isolated me
as surely as if I were far more contagious
has set me on the course of self-destruction
with no known cure

AIDS has disfigured me in grief
causing people to run from me
instead of staying to care and to love
(July '94)

Part of a poem I wrote three years after my husband's death. Athough not myself infected with HIV, this describes the parallel effects of grief and isolation.

While for some time I could barely grasp that I'd been a 'wife', suddenly there was diminishing permission to talk about the key relationship in my life. I couldn't comprehend why people now wanted to know about me and my future, rather than talk about Tony. `You've still got your life ahead of you' was the greatest threat anyone could throw at me.

Not feeling able to survive, kept subtly switching into not wanting to, until becoming more enmeshed in all the complications of grief, I didn't know the difference. Beyond that came a tendency to blame myself, and feel blamed by others because I was supposed to want to put all this behind me and move on. I periodically said 'I give up', yet didn't know what I had left to give up except life. Suicide plans at least shortened the interminable hell, so ironically played a significant role in keeping me alive...but, at their most serious, were additional reason to maintain the isolation which fuelled them.

Had I been able to break down totally in public the very first time I felt the urge, perhaps my path would have changed direction. As it was, the feelings of unreality increasingly overwhelmed me, most acute amongst people in shops, cafés, public buildings, and travelling. I felt safe – although grief-stricken – in places Tony and I had been together. Otherwise the formerly familiar caused a build-up of panic, disorientation, and a need to escape to the relative security of home, where I cried and cried. I had to give up work.

The people who'd been part of my life pre-Tony tended to trigger a fresh wave of unreal feelings, followed later by an onslaught of pain, fear, guilt and confusion. Everything ordinary now felt so alien, and to be reminded of the amenable, adaptable person I used to be, only exacerbated my utter powerlessness.

LOOKING FOR HELP

Apart from talking, and the hugs I craved but could rarely at the time feel, I didn't know what it was I needed of people, and so took the initiative less and less. There were stages when I resented even those who did persist. I oscillated between wanting and resisting dependency, further shaken by the slightest let-down. Absent people fast became, in my mind, non-existent, as if they'd disappeared into the same void as Tony. Only my letter-writing friendships continued completely unbroken: they had access to more of the real me at every twist and turn, and their responses confirmed acceptance, despite my desolation.

Secretly I longed for friends or family to force their way in and take charge, but instead, I fell between people. I tortured myself endlessly over why this was happening in addition to all else. Yet, each time I thought I was ready to emerge, I found myself lacking the sustained energy and will to reverse the trend and so would sink back into greater loneliness and isolation. I felt discarded by a world going on as before without noticing that I'd stopped still.

Television provided a replacement for company, a way of staying connected which was reliable and within my control. Pop songs, poetry, books, and some excellent radio plays on bereavement, were indications that my drastic state was not unique. Helplines were sometimes life-lines. Artwork and nature came into play when I felt most beyond human reach.

Counsellors and psychotherapists

Attempts to get professional help were fraught with many of the same complexities.

It was all very piecemeal, since no-one but myself – in a very debilitated state – was overseeing my care. Early on, a GP did ask me if I wanted 'to talk to someone', but my thinking then was that there was no point since it couldn't change anything. Anyway, waiting rooms gripped me in a full-scale panic reaction, so I was already in a shut-down state each time I saw the doctor.

In the end I did turn more and more exclusively to counsellors, detached figures. The best were strong enough to be unfazed by my honesty about how bad it was, allowing me to express and process strands of the chaotic profusion of reactions and emotions. Then, for a while, I felt real. Otherwise, I had some automatic way of adjusting how much I divulged according to how much I gauged they could take...and afterwards felt weary, confused, cheated, and angry (either at them or myself). I noticed, for instance, that I was only ever able to go through my necessary railing at God when invited by someone with profoundly unshakable faith, who needed neither to defend nor provide answers. Clearly spelled-out acceptance of whatever state I was in proved crucial.

After six months, all too aware of my lack of will to live, I managed to make enquiries and find a psychotherapist willing and able to take me on. At later stages of even deeper despair, I assumed my intentions of suicide meant I must quit therapy. When I risked admitting this, I was firmly told that it was perfectly all right to keep coming, whatever the outcome. This took the pressure off me, and actually allowed me to keep my one crumb of hope there in the therapy room at times when I couldn't hold it for myself.

During the third year I resumed work, warning those who knew me that it could precipitate my toughest time yet, but they seemed convinced everything would be fine from now on. In the event, I became extremely suicidal whenever I went home, no longer my one safe place. I rang the Samaritans, and got the perfect responses:

'I don't know what to say';
'You sound like you're in hell';
'People aren't listening to you'.

No evasion, no denial, no platitudes, no advice. I felt *heard*.

THE WEB OF GRIEF

The pain never lessened, it merely changed its form: grief – rage – fear – desperation – despair. Like air in a balloon, when squeezed from one part it rushed to distend another. Any progress was subsequently obliterated by a disproportionately large and long 'backlash', as I came to call the unmanageable emptiness and despair which usurped the place of any sense of achievement. The root of this was an unrelenting expectation that if I 'got it right' Tony would come back. In its grip, I was most at risk of self-harm – to appease acute emotional pain – and least likely to find anybody able to understand.

Whatever one's intelligence and reasoning, AIDS can still feel like a punishment.

I became progressively more entrapped and entangled in an impossible 'web' of grief, an interweaving of a whole range of emotions, symptoms and problems, contributed to and aggravated by isolation, and all encased in the outer 'wrapping' of AIDS. Thus I had to begin by addressing this first layer. The problems – society's denial, plus avoidance around death and mourning – were redoubled by the presence of AIDS in the picture, its aspect of sexual transmission adding a potentially damaging secrecy and shame. Whatever one's intelligence and reasoning, AIDS can still feel like a punishment.

Another obstinately taboo topic was the entire area of sexual loss, seemingly doomed to be sent underground, gone – as it had arrived – with Tony. Because no-one ever gave me the direct lead-in I would have required to talk this through, I got the message it was not okay for me to broach the subject, and that this precious dimension of my life so recently gained was to be treated as private to the extent of non-existence, yet another way in which all the rules had changed. I was left perplexed, with my mix of joy and upsurge of adolescent guilt unresolved.

WRITING AS THERAPY

It would have been hard, I suppose, for anyone to keep pace with me through the months and years of one step forward/three leaps back. I saw little of Tony's family in the far south of Ireland. My brothers were in England and Germany; 'phone calls, like travel, sent me into panic and unreality. My own family also remained emotionally distant, except for my aging mother who proved nothing short of heroic in her attempts to meet my need to express the grief, a struggle which, in the long run, meant her having to face her own ungrieved losses.

Writing was, throughout, the most enduring way of validating my experience and catching concepts clearly enough to work them through. Using old diaries, cheque stubs, dates of events, our photos etc, I slowly rebuilt my memory by writing out the relationship. As I went along, so came the feelings, and of course the grief. I could only do a little at a time, the process took many months; but once regained this way, the memories stayed put and so did their sense of reality.

I also wrote daily 'to Tony' for several years after I'd grasped that he'd never read any of it: I simply needed a 'you' to direct the outpourings to and it seemed a consolation for losing him.

In the fourth year I stopped abruptly and destroyed these writings. I grieved their loss, then developed more diverse ways of writing, some sharable, including fairy tales, memory cameos and, later, articles. All my poems I kept, an intensely vivid record going back to six weeks after Tony's death.

THE RECOVERY PROCESS

Tony's death had caused my grief and disintegration, but it was that relationship which also provided the incentive to come through to a better life. I had to reclaim it all, and go further along its path to catch up with the whole range of hopes and dreams, before I could freely choose to let go. At its most basic, no-one had been me, losing him – surely the essential loneliness of every loss. Bereavement books were useful and reassuring, except for the inevitable 'Recovery' section which rarely had much relevance to my own situation. And, time certainly did not heal: I was stuck in time and felt only dragged further from where I wanted to be, by clock and calendar, and others' expectations.

I believe the recovery process, and those ingredients necessary to sustain it, to be a highly individual package. Although I felt at an utter loss as to who or what could help, or how or where it would lead, at another level I think I instinctively knew just what I needed stage by stage. My consistent cry, usually silent, was to 'Let me be (exactly as I am) without leaving me (abandoning me).' Then I didn't have to do it all in such isolation nor feel both a freak and a failure.

Just a hand reached out...

Why is it the bereaved can't be treated with the equivalent ready and willing attention given to the dying? Is it for fear there'll be no end to it? In my own experience, adequate care available promptly pays dividends, and makes dependency a passing, if acute, phenomenon.

The people around during Tony's dying weeks constituted a temporary family, and vital human stability. Soon after his death, and also much later on, it was wonderful to be able to find some of them again, be

welcomed, and have details remembered, such as the night nurse who brought tea at 3am during our last (and only) night at the hospice, and sat on my bed whilst Tony slept, to chat and look through our photos of home and wedding.

From the hospice onwards, what mattered was people asking questions rather than making assumptions, being moved without being themselves shattered, and treating each stage as important (not some 'factory production line' grief). Everyone could help, from ward domestic and undertaker's receptionist, to first contact at Cruse. Just a hand reached out, or a shared pot of tea could feel like somebody saving me from drowning, whereas the hugh loss seemed to be insisting 'You have to do without touch too, now, so you'd better get used to it.'

A network of professional support

My five-year psychotherapy path ran through many a rocky or precipitous stretch when it felt anything but supportive. As each underlying cause was focused upon, an additional burst of grief work became necessary. At first it was the psychotherapy room itself that I clung to as most important, then a year or so later, the relationship itself. But I still had to get through the days and weeks between sessions: the hell in between the help.

Two years on, residential workshops* provided a generous measure of support: the trappings of 'normal' life set aside for between two to five days, and every expression of strong emotion encouraged, in safe surroundings and guided by a skilled team practised in clearing their own feelings likewise. A shock contrast to isolation, I did struggle at social times like meals, but there was an ease in relating to others when 'masks were down'. I left each much the lighter and more hopeful.

At the two year mark I followed through an earlier visit to Cruse and requested a counsellor there as well. This resulted in access to a vital continuity: someone who had no problem with seeing me occasionally, whether the gap was weeks or years, no surprise at or judgement of my timing. No matter if I was at a very positive or all-time hopeless point, here was a key figure who could relate how I was now, to how I had presented at earlier stages, and pinpoint the particularly difficult juxtaposition of so much happiness and grief in such a short space of time.

Over three years after Tony's death, a two-leader weekly bereavement group became available and, despite the lapse of time, it met my need to share the grief experience deeply and in all its rawness with others. Its premature ending, halfway through for me, left me disappointed, yet satisfied that the few sessions had been exactly what I'd longed for.

Looking back, I notice it really helped to have a selection of support figures, preferably in some sort of harmony of approach: people I could go to for a while, leave whenever I felt ready, or got frustrated because what they were offering didn't seem to be the answer, and maybe later return to, even though I'd thought I wouldn't want or need to. Hospital social worker, community psychiatric nurse, Cruse counsellor, and the priest who took both wedding and funeral, all have fulfilled that role in one way and another, as eventually did the therapist too. It was years before I discovered that a 'final goodbye' didn't always have to be final!

A sense of empowerment came with being able to question, and in time dismantle, part of the support network, or feel it teeter without danger of total collapse. An assurance of reliable commitment, 'for as long as it takes', allowed me the choice.

The search for closeness

It seems I searched (when I could manage it) for people who genuinely cared, yet had the wisdom and overview that is maybe otherwise provided by family or close friends. I have increasingly managed to acquire this sort of support for myself, but was too dazed and distressed to do so then.

Why is it the bereaved can't be treated with the equivalent ready and willing attention given to the dying? Is it for fear there'll be no end to it?

Unexpectedly, perhaps, it proved just as vital to have such people to report better times to; otherwise, without someone who really understood what it had taken to get there, these could be every bit as lonely and fearful as the bad times. Later still I found extra value in asking someone to share and witness a symbolic occasion, such as returning shells to the sea or planting seeds in soil.

Throughout, those who I remember most warmly were open to learn from my frank sharing of the all-consuming pain, and risked telling me they felt personally enriched. It was all I felt I had left to give.

RESOLUTION

Ultimately, it was within the pain-filled isolation (that horrendous state of being so little known by others) that I got to know myself and found my own identity intact. I had to learn to recognise and be patient with the panics, the infantile reasoning and behaviour, the inevitable backlash pattern. My ability to feel and my need to understand appeared to move with alternate steps. Alongside came the creativity and strengths needed to emerge, in fits and starts, with new depths, and a certainty that nothing had been lost or wasted.

When the grief seemed over, I found I was able to sew a panel for the AIDS Names Quilt. Previously I'd wanted this to be a joint project but planning and stitching it alone turned out to be appropriate, since my grieving was done that way. It has turned into an extravaganza of colour, texture, and style, soon to join the rest of the Belfast panels and be used for exhibitions and AIDS education, a unique tribute to those who have died.

Have I 'recovered'? Certainly I am at peace with our relationship right through to, and beyond, its ending, and feel enriched and strengthened. Let-downs and unexpected losses are apt to throw me temporarily into former patterns of losing trust in life. Success and things going well bring shadows of fear and insecurity. The major turning points – moving house, ending therapy, anniversaries marked by letting-go rituals – did not, in fact, bring all the expected changes.

The limitations of 'professional relationships' – where it always lay with me to be the one to make contact, and at the end of the day I was just 'part of the job' – eventually drove me elsewhere. But I remain convinced that it is only as a result of this help that I became increasingly open to the simple healing of human kindness and ordinary friendship.

My renewed enthusiasm for the stuff of everyday life, and my ability to make easy choices and good decisions, assure me of a healthy sense of direction. Articles such as this, involvement in neighbourhood and community, and my availability to others isolated by trauma and despair, are all aspects of a completion in which the impact of grief on my life is converted into a positive presence. **BC**

*'Life, Death and Transition' Workshops, with facilitators trained by Elizabeth Kubler-Ross in the externalisation of feelings.

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