

Co-research: The making of an alternative knowledge

by David Epston¹

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Chapter 16 in 'Narrative Therapy and Community Work: A conference collection' Dulwich Centre Publications 1999.

Co-research was a term I concocted in a very specific set of circumstances to describe to myself and others a practice at considerable variance to 'family therapy' of the late 1970s. Around that time, I began a very valued association with Dr Innes Asher, a respiratory physician at the Department of Paediatrics, University of Auckland. We began to collaborate around those children, adolescents and their families who were suffering the experience of life-threatening, chronic and often disabling asthma. Such suffering, as I was to learn, had no 'voice', no vocabulary and no place in the biomedical discourses. If anything, it was rigorously excluded. A 'good patient' was calm and enduring, and such manners were certainly expected of the family members concerned. But such a life-threatening asthma, referred to as 'brittle', could happen almost any time day or night, seemingly with little or no warning.

Ronny's story

The first young man I was to meet was twelve. By then, Ronny had suffered numerous respiratory arrests, each one threatening his life, following his first arrest on the occasion of his eleventh birthday party. What made matters grave was that he had also started cardiac arresting, although his heart according to the cardiologists was 'as strong as an ox'. His parents, who lived a 60-kilometre ambulance ride away from the Children's Hospital, could only submit to two sleepless nights before Ronny insisted on returning to the hospital. He was so concerned for his parents' well-being. Such was the hospital's concern for him that a suggestion had been floated that he live in intensive care. Everyone worried that he did not have long to live.

In fact, I noted when talking to hospital staff involved in his intimate care, they would betray their fears for him without even knowing it - a slight tremor at the mention of his name. However, as I canvassed everyone, a nurse on the night shift told me a story I will never forget. She has to remain nameless because by the time I realised its significance, she was lost in the regular rotation of nurses throughout the hospital.

One night when Ronny rang his night alarm, she raced to his bedside and found him in great distress. This usually signalled an arrest. However, at the same time, she was summoned to another alert which had priority and there were no other nurses available at that moment. She had to leave Ronny. She called upon all her courage, looked Ronny straight in the eye and shouted 'STOP IT!' They were both stunned by the fact that his distress immediately abated and she was safely able to leave him. Although this had been duly noted in his 'medical chart', it went unattended to, a mere curiosity. This incident, considered at some length, became foundational to a 'courage practice' that was trialed with consent under the most hazardous conditions. I was permitted, in a manner of speaking, to give him asthma attacks. I had noticed that my mere mentioning of the word 'cough(ing)' was more than sufficient to bring on extreme wheezing. With Dr Louise Webster on medical guard behind Ronny and me, we commenced to 'arrest arrests'. For example, when he was mildly distressed, I would offer him a handful of coins and ask him to pick one. I would then ask him to read the date on it. My next question, 'Ronny, what was it like to arrest an arrest?', was met by great bemusement. On each trial, I allowed his wheezing to worsen until the final occasion. He began to lapse into semi-consciousness, turning an awful blue. Dates on coins were no longer of any interest. I seized his hand, gently squeezing it, repeating 'Feel my strength passing into your mind and body'. I sensed I was losing him at the same time as my strength was running out. With my last gasp, I fiercely squeezed

his hand and shouted 'STOP IT!' To everyone's amazement, he did exactly that and stopped it. Obviously confused, as a full day had been dedicated to 'arresting arrests', he jumped to full attention and rushed out of the room like the Mad Hatter saying that he was late for an important x-ray date. The nurses from the nearby nursing station rushed in, seeking information. Louise shouted, 'He did it!' and, like wildfire, the news spread around the ward and beyond.

Ronny was soon able to return home to live, had only one further hospitalisation, and was able to resume a normal life. Innes and I have kept in touch with him one way and another ever since.

Acknowledging alternative knowledges

This experience with Ronny was formative in convincing me there were 'alternative knowledges' to the more conventional treatments for which Ronny had exhausted each and every possibility. What was particularly significant was where one might seek such knowledges - the metaphorical space created through an externalising conversation between the person/family/carers *and* the illness/disability.

Family therapy theory and practice in the late 1970s and early 1980s had also considered this, but I found them at worst 'family-blaming' and at best 'family suspicious'. Lyman Wynne summed up this state of affairs in 1992:

The family system explanations of illness can be regarded as an alternative version of the societal and traumatic life-event interpretations of illness. In each of these versions, not the individual but a larger social unit (family or society) is viewed as 'disturbing' or 'sick'. The hypothesis is that family systems are causative in generating or maintaining symptoms provided much of the impetus for starting the field of family therapy. (Wynne, Shields & Sirkin 1992, p.13)

Concerning life-threatening asthma whereby family members had been involved in numerous life-saving incidents, either directly by administering CPR or indirectly by calling ambulance or intensive-care services, for me to operate on a family-suspicious basis seemed a grotesque travesty of benevolence, let alone a professional practice of therapy. I became determined to find an alternative frame of reference so I might meet these people with compassion rather than suspicion. First of all, I took 'suffering' to be the designated 'problem'. And by doing so, 'suffering' more or less became everyone's problem. And such suffering was beyond the scale of anything I had known close up. Unfortunately, there was more to come.

From empathy to ethnography

In the late 1980s, I felt I had no choice whatsoever but to further this endeavour to find an alternative when I met the membership of the Dystrophic Epidermolysis Bullosa Research Association. Although this is retrospective, I believe I got the word 'research' from sheer plagiarism. When I was first contacted by a colleague, Nick Birchall, a paediatric dermatologist, I recall being at pains to first learn how to pronounce it and then find out what in the world 'DEB', as it is known, was. He informed me it was a very rare genetic disorder variably affecting around 70 individuals in New Zealand. What I did remember most vividly was his description of a missing gene that metaphorically meant that it was like concrete without reinforcing steel. Without such reinforcement, the skin is extremely vulnerable to blistering or rupture at the slightest pressure or touch. The pain associated with this was so excruciating that lancing by razor blade is the only means of relief. Because of the many wounds, parents have to debride their children's skin before bandaging it, which is felt to be as painful as intentional torture.

There was no way whatsoever I could have been prepared or could have prepared myself for the prospect of parents being obliged daily to act towards their children in ways everyone knew was inflicting excruciating pain. Young children could not be expected to mediate such sensations into dignified suffering. The pain was just too painful to be distinguished as benevolence or care. I found myself just running out of empathy - if that is the capacity to step into another's shoes. This was truly outside of what I could conceive. Nor could I fathom what it might be like to revive a comatose child who was arresting and

how such a hazard could ever become a part of my everyday life. I felt like an alien, and the very best I could hope for was a very rough translation, however uncertain and circumscribed by the limits of my own experience.

I had to ask myself - to what extent can a person participate in another's feelings or ideas? After all, empathy rides on the faith that the grounds of experience between myself and others are similar, such that I can know what another is feeling, based on what I might feel in such a situation. But what if the situation remains beyond your grasp, despite your best efforts to imagine yourself into it?

I decided to take ethnography (or, better put, the *doing* of ethnography) as my means of operating. Rather than thinking of myself as possessing some 'expert knowledge' that I might apply to those consulting me, I made seeking out fellow-feeling as my primary concern. After all, in every instance, the various expert knowledges had exhausted themselves of their very own expertness or frankly admitted that they could do no more than palliative care. For me to presume to substitute some sort of 'psychological' expert knowledge would have been insolent and immediately rendered me 'suspicious'. By the same token, my 'suspiciousness' could very well have been experienced as blaming, as had often been the case, despite my best efforts to redress that.

Other questions I was asking myself were:

- How could I request people in peril to stop seeking rescue but rather turn to themselves and each other?
- How might I proffer something other than a 'miracle cure' to take the place of the forsaken 'medical cure'?
- How could we all take up different relationships with each other and the problem of suffering?

I had observed that the discourses of biomedicine and the discourses of miracles produce patients and petitioners who fervently looked beyond themselves for 'cure' and/or 'salvation'.

I chose to orient myself around the co-research metaphor both because of its beguiling familiarity and because it radically departed from conventional clinical practice. It brought together the very respectable notion of research with the rather odd idea of the co-production of knowledge by sufferers and therapist. What made this possible, in the first instance, was a fairly thorough-going externalising conversation, one in which the problem was a problem for everyone - and here I included myself. Here's where I parted company from the disinterested ethnographer. This has led, and continually leads, to practices to discover a 'knowing' in such a fashion that all parties to it could make good use of it. Such knowledges are fiercely and unashamedly pragmatic.

Ashley's story

Ashley was not yet three years old when his parents, Colin and Kathy, approached me about his severe dystrophic epidermolysis bullosa. They sought for me to prescribe his future and theirs, something I was quite unwilling to do. Instead we commenced to co-produce a sufferer's or insider's knowledge under the umbrella of reducing their suffering in general.

The Dystrophic Epidermolysis Bullosa Research Association became a precedent for what I have come to refer to as a 'community of concern'. I commenced advertising co-research practice in a very scrupulous and transparent fashion. It was advantageous, to be sure, that they themselves used 'research' in the very naming of their association. So difficult and rare were their circumstances that many swore they owed their very lives to the existence of their annual conventions and the forum of their quarterly magazine. With everyone's consent, I made it my practice to circulate the letters I wrote to one family around their community, thanks to their newsletter. At the annual convention, a day would be set aside for co-research. In the morning, I would review whatever co-research projects were underway (for example, the project Kathy and Colin and I had evolved, which I will show you immediately) with all their 'community' of

around 200 people gathered around us. In the afternoon, groups would break into what they ironically called 'case conferences', made up of children, families, extended family, friends, and professionals to reflect on the 'knowledgeableness' of the family concerned. Such a knowledge would then be considerably enriched. Their own knowledges - often miles apart - were often evoked when referencing their own experiences with DEB against the co-researching agenda. Thrilling surprises were always in the air, which often set the co-research agenda for the next year. To bring this all down to earth, here is the first co-research letter circulated through the DEBRA Newsletter.

Dear Colin, Kathy and Ashley,

It was very pleasing meeting up with you and starting a conversation which I hope we will continue in the future. On my part, I am just getting to grips with DEB and the particular problems it presents to young people and their families.

First of all, I think it is important for me to set out my thoughts for your consideration. I am totally unconvinced that the answers you are seeking for Ashley exist within any professional knowledge. As far as I can see, medical knowledges don't apply themselves to the day-to-day problems confronted by Ashley, yourselves and your community. Many people seek that day-to-day knowledge from doctors and are sadly disappointed and at times angry. My position is very dissimilar. I propose that the knowledge, so particular to Ashley and yourselves, be developed by yourselves in co-research with me. That is, of course, if you wish my assistance. Co-research implies, firstly, that the answer is unknown but, secondly, that it can only be discovered by an experimental attitude on a day-to-day basis. Co-research is also based on the belief that parents and young people can find their own solutions to some of the effects of their medical problems, or at least reduce the effects of such problems in their lives and that of their families. An experimental attitude draws upon something parents already do, and that is the close observation of their children and their activities, noting small differences. This approach sponsors flexible solutions, ones that fit the particular developmental circumstances of young people and their families.

We discussed a number of points, some of which I thought might profit by further consideration, both by you and me. Kathy and Colin, you both would like to know conclusive answers to some very important questions regarding Ashley. I urged you against seeking this kind of information. Instead, I counselled you to raise a number of questions to your conscious awareness, all the better to experiment with. Instead of conclusions, I propose balance. I have found that those people who seek conclusions blind themselves to chance discoveries. They want the right answer when, in fact, there is no right answer. What happens, then, is for parents to choose parent-supervision as the right answer, and if or when that doesn't work, to choose child-supervision in its place. All the time the search is for the right answer. An experimental approach concerns itself with balance or, better yet, finding the balance between, say, parent-supervision and child-supervision (self-supervision). This allows for flexibility and new learnings. For example, in some circumstances, say learning a new skill, it would be more helpful to start out with 95% parent-supervision but then start tapering off so that by the time it becomes an old skill, the balance is now 95% Ashley supervising himself and his parents supervising him 5%. These balances will also reflect Ashley's age and stage and current levels of ability. So there is no right answer; there is only balancing, and that is an act that everyone can enter into.

We talked in general about three basic dilemmas that need to be balanced if Ashley and his family are not to become unbalanced (and I have certainly seen that happen with young people who must struggle with chronic health problems):

1) Parent-supervision/child-supervision.

The hazard of many young people and their families, as we discussed, is the tendency for parents to supervise their children well past the time when their children, if they did not have health problems, would be supervised. You must have seen many examples of parents of chronically ill children being vulnerable to over-supervision. Many of these children are particularly vulnerable to inviting their parents to over-

supervise them at the same time as under-supervising themselves. This can lead to a 'disabling' vicious cycle, with parents supervising them more and their children supervising themselves less. The parents can forget to supervise their own lives and, as a result, they often become problem-centred and the family life (or what's left of it) revolves around the problem. The opposite or 'enabling' virtuous cycle sees parents inviting their children to supervise themselves more and, by doing so, they invite their parents to supervise them less. Now, Ashley is only 3, and in the above I am talking about children aged 1 to 17. Still, from speaking with you, I could see how you were giving Ashley some 'space' to supervise himself (and pay the consequences). Of course, your parent-supervision comes in, say if Ashley unwisely supervised himself and the consequences of his decisions were too harmful to him. Still, with DEB, I guess the only way to learn is the hard and painful way and the sooner he is able to decide wisely, the better. The above is merely a framework for a 3-year-old Ashley, remembering that the balance for a 4-year-old Ashley will be a bit different.

2) Taking pressure off Ashley in regard to his problem/putting pressure on Ashley in regard to his problem.

Taking the pressure off and putting the pressure on is something of a restatement of the above. Once again, there is a problem of balance and the scales probably shift on a day-to-day basis, depending on Ashley's well-being. However, these terms allow you to revise matters on a day-to-day basis. For example, 'Ashley, today you suffered a fair bit, so we are going to take the pressure off you', 'Ashley, you had a good day today, so we are going to put some pressure on you, so we are going to expect you to clean up your toys', etc.

3) Self-sensitivity/other-sensitivity.

Self-sensitivity and other-sensitivity: this is a critical issue for young people and their families. Having a chronic and painful health problem leads many young people to be exquisitely self-sensitive, as you might expect. It can also lead their parents to be very sensitive to them. This can lead, in turn, to a young person becoming very insensitive to others, particularly their parents, and many parents, especially mothers, becoming very insensitive to themselves. In the end, you have a young person who is self-sensitive/other-insensitive and parents, particularly mothers, who are child-sensitive and insensitive to themselves and their relationships. Once again, this is a question of balance, a balance that is constantly shifting. If you have kept this dilemma in mind, I can't believe you would allow matters to get out of balance much before you would make readjustments.

I wonder what you think about the above and if you think this would be useful in providing a 'map' for deriving experiments, experiments that won't provide you with a once-and-for-all answer but rather day-by-day answers. I believe, too, that the more you apply these dilemmas, the easier it will be to rebalance, should you consider it necessary. I'll stop here. Sorry for taking so long in getting back to you. I look forward to hearing from you and meeting up with you again. Feel free to send me any of your 'stories', which I hope in due course will be compiled by your Association and circulated from one family to another. These 'stories', when read together, will provide the reader with a sufferer's knowledge, a knowledge particular to the everyday life of a young person with DEB and their family. I look forward to assisting you, in any way I can, with this venture.

Best Wishes

David

The archives of the Anti-anorexia/Anti-bulimia League

Having considered the history of this co-research work, allow me to pass rather quickly to what I have been referring to for almost a decade as the archives of the Anti-anorexia/Anti-bulimia League. The problem of so-called anorexia/bulimia have consumed me up until recently. Anti-anorexia allows us, if we listen

carefully, to hear what Anorexia has to say and how it says it. But it does not tell us its purposes or causes. That is for all of us to find out. How does anorexia enter a young woman's life, impersonate her for a period of time, before becoming her cruel ventriloquist? What is so frightening is that the words coming out of so many mouths in any number of mother-tongues are so much the same. For reasons such as these, should we then concern ourselves as to what is this 'power' that is pulling so many strings on so many lives? Furthermore, how does such 'power' spin so many deadly webs that entangle so many young lives, bleeding them of hope so that nothing but their annihilation is imaginable? How does anorexia conceal itself so that it can proceed without much resistance to speak of, or hardly any public outcry? Anorexia's 'power' is so treacherous, so insidious in fact, that it has young women torture and violate themselves while it remains in the shadows of their lives stalking them. Anorexia not only claims its innocence but goes further than this. It now promises these young women the means to escape the very web in which it has ensnared them. They are told that the strict adherence to anorexia's regimes of rules and regulations will 'set you free'. They are soon to learn that they can never satisfy anorexia and are now on a 'diet to death'. Each and every attempt to reach the anorexic standard, and their inevitable failure to do so, unwittingly tangles them more into the web. And the web now starts closing in on them, slowly but surely squeezing the life out of them.

It has always been my practice to heavily document it from my very early days as much for self-protection as anything else. Bob Dylan sang something to the effect that: 'If you are going to live outside the law, you had better know what the law is!' The philosopher Michel Foucault advised the documentation, authentication and circulation of 'alternative knowledges' if they were to do what he proposed was their work - that of critique. I have always kept this in mind. Anti-anorexic documentation has taken many forms, and the 'itineraries' of their circulation have become international, now being carried by fax and email. Perhaps the five boxes currently stored in my garage will soon move to some book, hypertext and/or electronic home.² To be sure, I'll still keep my boxes of archives as back-up.

Why did I choose the term 'archives' and come to think of myself as an archivist? First of all, an archive, according to the *Concise Oxford Dictionary*, 'is a place where public records are held'. In the early days, the archive operated in a very crude way - I would Xerox copies of archival material and post them on request. These archives have been both a resource to and exemplary tales of a 'counter-practice' - commonly known as anti-anorexia/ anti-bulimia - to what I refer to as the social practice of anorexia/bulimia.

Many have called upon these archival documents to inspire their own resistance. Often those who loaned the documents later wished to contribute their own. The most common response to being read a document has always been, 'Can I have a copy that?' This growing body of documents - these fragments of an 'alternative knowledge' - needed a name. *The Archives* was an obvious choice. Its main purpose was to merely store in good care and find ways to index it so anything could be easily retrieved. Many of the first generation of League membership bitterly complained that the various professional literatures concerning anorexia/bulimia either dismayed them or made them actively ill. The more autobiographical genre of the 'I am an anorexic' type seemed to offer readers little chance for escape. More than anything else, it remains a literature of despair.

I envision such an archive of resistance to be both a resource and a platform for anti-anorexic developments that are as yet currently unimaginable to me. I hope too that it will be the means to a movement that will operate both underground and above ground to conscientiously object to, resist and finally repudiate anorexia and bulimia.

I suppose by now 200 to 300 people from around the world have contributed to it, although not every document forwarded to me has been included. Most made their contribution for the express purpose of fostering disobedience and protest to anorexia. Many of the contributors suffered dearly for having done so by various forms of anorexic torment, but they did so nonetheless. Still, we should remember that. It is more than a decade old now, and sadly I have lost touch with some of its most notable contributors. But what wedded us all together into a 'community of concern' was this archival knowledge that provided a place to speak from and retreat to.

Such records of resistance tell too of the horrors and inhumanity of anorexia/bulimia, and lift those up who have suffered and are suffering **so that we can witness their testimonies, keep their legacies alive and, most importantly, pay them our respects.**

Speaking anti-anorexia - an anti-language

The documents within the archives can take many forms, as you will see, but what is common to them all is their *manner of speaking* - anti-anorexia - an anti-language, a radical form of an externalising conversation.

The following quotation is one of the first public statements by the so-called ‘anorexic’ Ellen West written prior to World War II. She was later to suicide. Or was she executed? But first let us listen carefully to her words, the only manner of speaking she had to express the horror of her life:

I don't understand myself at all. It is terrible not to understand yourself. I confront myself as a strange person. I am afraid of myself; I am afraid of the feelings to which I am defencelessly delivered over to every minute. This is the horrible part of my life; it is filled with dread. Existence is only torture ... life has become a prison camp ... I long to be violated ... and indeed I do violence to myself every hour of the day. (Binswanger 1958)

If she could have spoken anti-anorexically, she might very well have proclaimed her conscientious objection to anorexia rather than such a confession of her supposed offences:

Anorexia, why are you trying to confound and confuse me so that the contradictions I experience as growing up as a woman in the Third Reich are obscured? Why did you appear just when I started to make myself up? How did you turn my critique into my estrangement? Why would you want to turn me against my very desires, wishes, opinions and appetites? And if I were to reflect with a community of like-minded women upon such matters as how and why you conscript us into prison camps where we are defenceless against your tortures and violations, might we turn against you rather than our bodies, minds and spirits?

In my experience, once provided with the means to speak against anorexia/bulimia, almost to a person, everyone aged 12 years of age and over has railed against many of the ‘psychological’ and ‘psychiatric’ constructions of them as ‘anorexics’ or ‘bulimics’. The ‘stories’ from the insiders are incomparable to the stories written about them by outsiders. Why is it that insiders regularly refer to anorexia as either a grotesque manifestation of evil or the devil, when such terms have otherwise been consigned to the dictionaries of the histories of words?

Documenting knowledge-in-the-making

What is most important to me about the archives is this: that the documents record knowledge-in-the-making and reveal it as such. There is no wish at all to use the conceit of ‘completed knowledges’ that promise to have all the answers. By comparison, the archive would wish to provide some of the best and most poignant questions and pertinent lines of inquiry. I am referring to the distinctive ‘reading’ the archives call for as *resonation*. The archives are read for inspiration rather than right answers, prescriptions, etc.

Here are some of my favourite questions to a person with whom I have just shared an archival document:

- *Lee, did Judy's account of her betrayal by anorexia ring any bells for you?*
- *Lee, did Judy's account of her betrayal by anorexia enable you to see anything about anorexia that it had been blinding you to up until then?*
- *Lee, did Judy's account excite your mind in any anti-anorexia way? And if so, how?*
- *Lee, were you able to connect in any way, shape or form with Judy's account?*

Since most documents are knowledge-in-the-making, most people resonate to this, although they may or may not concur with specific conclusions.

Robyn's unmasking of anorexia

One video document that has proved to resonate with many people's experiences has been Robyn's unmasking of anorexia.

David: Robyn, from what you have been telling me, does that mean you have unmasked Anorexia?

Robyn: Yes I have. In fact, unmasking Anorexia is crucial. It is the crux of the matter.

David: Can you tell me how you registered Anorexia unmasked for the first time?

Robyn: I had a fight with my parents. Fights usually herald several pro-anorexic days because, straight after a fight, I can't eat. It's like a button being pushed. I was tremendously upset and decided to hide down by the pool in the back yard. I then saw this ugliness that scared me witless but, at the same time, I was able to face it. I really identified it as an evil spirit. I felt its grip ... its bite. We were locked in combat for between a quarter and half an hour. It started with panic and guilt over what I had eaten over the day. Physically, I was feeling sick. I felt a gut dread ... an unfocused dread. But then for the first time, I saw its true face. I had never seen anything so hideous. It's a monster, black, with indistinct features. It was more an emotional concept. MY TORTURER. It did manifest itself as a force of being, an evil power. I got the feeling I could oppose it. I struggled with it in hand-to-hand combat. I prayed to strengthen my resolve. I won that fight but it wasn't a fight that was all mine.

Robyn then paused for several moments and, becoming far more relaxed and even serene, she proceeded with a kind of summary:

I've seen it now. It will never come to this again. I've seen its chilling side ... its cunning side. THE UNMASKING OF ANOREXIA is crucial. I think I know what it is now. Now when it tries to trick me, more and more I see them as tricks. It all began when I was 16, when I started blossoming as a person and had just started flowering. Anorexia takes away your ability to govern your own life and make your own decisions, and replaces this with a crutch, a false refuge, somewhere to run away to. Anorexia separated me from my hopes and dreams. It made me passive and out of the world. It disconnected my logic and my heart. It was as if my life was happening to me and I had no say.

Carla's story

Sometime after the making of this video with Robyn, I was to meet Paula Parsonage, a counsellor working for Community Alcohol and Drugs Service (CADS), through a decidedly strange set of circumstances. I was contacted by Kathy Menzies, the Director of CADS, asking if I would provide six sessions of counselling for Paula. This was the agency's protocol for any counsellor 'losing' a client. 'Why me?' I asked. I obviously misheard as I thought Paula's client had died of anorexia. I asked if I might contact Paula myself, firstly to give her my condolences, as well as make a time to meet. Kathy said that would be unwise as Carla hadn't died yet; rather she had recently been declared 'terminal' at a meeting Paula attended, along with Carla's family and all professionals associated with Carla's care. Paula, quite extraordinarily, refused to withdraw her services, although all other professionals agreed to do so. I immediately asked Kathy if she would be willing for me to use the 'posthumous sessions pre-humously'. Kathy laughed, thought for a moment, and agreed to this.

Paula, Carla and I met soon after. Carla was 38 and had had, according to her, 55 hospital admissions over the past 23 years ever since anorexia took over her life after she was sexually assaulted. She lamented how she had always, for as long as she could remember, wanted to be a nun and live a religious life. However,

since this offence, anorexia had, in a manner of speaking, excommunicated her, forbidding her to enter a church, pray in private or even hang her cherished pictures of 'Our Lady' and 'The Bleeding Heart'. I surmised that over the course of so many hospital admissions, she would have had her fill of being asked questions. She heartily agreed, but probably was left wondering how we would fill our time. I proposed that we consult the archives and that I would read from them. Included in my readings was Robyn's unmasking of anorexia.

The following letter details our next meeting.

14.5.93

Dear Carla and Paula,

Carla, Paula and I certainly felt a long way behind you in terms of your anti-anorexia. And I was touched to learn that all the laughs we shared in our first meeting was the first time you had heard the sound of your own laughter in over 20 years. I wish I had been aware of that at the time so I could have relished each and every one of your laughs and jokes. Anorexia does require people to be deadly serious and, to be quite frank, I think it's deadly boring.

After our first meeting, you told us of the onset of some 'uncanny experiences, religious in nature', which provided you with an anti-anorexic vision. When we got thinking about it, your vision came to you something like the visions Robyn documented in the League archives.

Carla, why do anti-anorexic visions take such unusual avenues to bring new thoughts, ideas, etc. to your conscious mind?

Carla, do you think these visions were an expression of anti-anorexia bursting through the defences of anorexia and the spell it had cast over your life for the past twenty-three years of 'hellishness'?

What you told me about your vision was this: 'I've lived this long. There must be a purpose in it. I am a FIGHTER and have survived so many physical ailments'. And you suspected that it was your personal faith and spirituality that was at the bottom of this. You wondered if it might be Our Lady, and then told us how anorexia had 'forced me to neglect her'. In your visionary experiences, you were able to see a future for yourself, even though it is as yet unclear.

Did anorexia tell you that you were unworthy of your faith?

Did anorexia try to strip you of your very soul?

Was a hint of the future refreshing to your soul? Did it hearten you in any way?

Through this visionary experience, you thought you now had embarked upon an anti-anorexic direction. To do so, you must have broken the spell of anorexia. Can you record for the archives your 'first steps', because the 'first steps' are always the biggest steps, even though they seem minuscule at the time?

On reflection, you thought the fact that 'I didn't believe in myself' may have advantaged anorexia in deceiving you into believing in its promises of salvation. And you wondered, too, if 'I hadn't been searching in the wrong direction. I was hoping for something to drop out of the sky'. When did you realise that anti-anorexia could only be gained by resistance and struggle? How did that dawn on you? In fact, you said of late, 'I am getting more positive and starting to believe in myself'. And this is in the face of anorexia's attempt to isolate you and drive you to self-execution, one way or another. For example, anorexia has got you out of practising the art of conversation and tried to convince you that you were nothing but an 'anorexic' and that there was nothing left of you as a person.

In your visionary experience, you turned against perfection too. It provided you with a rallying cry: 'NOBODY IS PERFECT!'

And it made you fully aware of the trap anorexia had ambushed you into: 'The more you try to be perfect, the more inferior you feel. The more people blame you for anorexia, the more you feel like a second-class citizen. And then you start to feel that anorexia and its torture, punishments and enslavement is what you deserve because you are no longer normal.'

Both Paula and I witnessed a lot of your self-confidence shining forth. This is what you had to say: 'I am working on getting some sort of control over my life'. This didn't satisfy my curiosity and I asked more questions of you. You replied: 'My faith is mine again. All this is happening for some reason. There is some power behind all this.' Well, I was convinced of your power, although that is not to take away from the power of anorexia. As you told us, you had previously thought that if you just went along with anorexia's demands and requirements of you, you would finally satisfy it and it would leave you alone. You then found out to your dismay that it would not rest until it had you sign your own death certificate.

It was now you cried out those slogans to rally your spirits:

NOBODY IS PERFECT!

I'VE GIVEN UP TRYING TO PLEASE MEMBERS OF MY FAMILY

I'LL PLEASE MYSELF INSTEAD!

I'LL GO MY OWN WAY!

You went on to tell us that 'I used to feel guilty if I ever did anything for myself to make myself feel good', but that now 'I feel that I have come out of a dark hole ... out of a nightmare'.

Anorexia is a formidable enemy, but anti-anorexia is just, is it not? And I believe justice should now be on your side. And in addition, is there some divine presence behind what you refer to as those 'uncanny things'? What do you think of the fact that you can now 'pray well' again after all these years? And that you stumbled over the Old Testament verse of 'a time for everything - a time for war and a time for peace'?

Carla, I submit this question to you with the utmost sincerity. Is it your time for an anti-anorexic crusade? Has peace and submission to anorexia brought you anything but your near-annihilation? Is your anti-anorexia your holy cause? When I asked if anorexia had ever taken your soul, you fervently denied this and reassured me that that had never been contaminated by anorexia.

Yours anti-anorexically

David

What the League has meant to me

I would also like to tell you what the League has meant to me. For me, this work has been extraordinarily difficult on so many fronts. How many limbs have these families and I gone out on, that if one broke, death would have been very likely. I cannot tell you how often in the solitariness of my office, I too would appeal to the League, embodied in its archives. I have lived for several years now with the comfort that Lee, Sarah, Brett, Bryce, Paula, Fran, Eva, Gloria, Jenny, Jo-anne and so many more are both behind me and beside me. Anti-anorexia has become my place too to stand and speak from, for at times you can feel invisible - even though you're not - but this is certainly worth entertaining when you work against evil.

The Leagues as 'friends-in-arms'

To end, let me tell one final story. Mary, aged 17, had pulled herself out of the quicksand of anorexia in 1997 and 1998 for the time being. It was painstaking for her parents, Warren and Sharon, and myself. However, when she was faced with her final secondary school examinations late last year, we all feared that every freedom she had reclaimed had been forfeited and she would perish. Warren, usually a strong contributor to any anti-anorexic matter at all, sat with his head bowed, tears running down his cheeks and pooling onto his shirt collar. Sharon, also a strong and thoughtful commentator, seemed frozen into stillness and glacial silence. It seemed as if Mary had come to say farewell. I found this unbearable and wrote to her from the very 'heart' of the archives.

Dear Mary,

I wanted to write you after our meeting on Thursday. I strongly felt Anorexia, once again, pulling you away from us and down, insinuating that there was no other 'world' for you other than his Hell, where you might sit beside him as his Queen. It was unnerving for me, and, judging by Warren's helpless tears of frustration, it is for us all. Before I had time to put my fingers to my typewriter, your mother rang to reassure me that you were able to come back to us a bit. That was a great relief to me, and I know it was to Sharon and Warren. However, it did delay my response.

Mary, I am writing to you in defiance of Anorexia and all that it stands for. I swear to you - and all those murdered by Anorexia are my witnesses - that nothing will prevent the League from keeping a 'place' open for you - a place to stand and take a stand for your life and entitlements to happiness, peace and fulfilment. Admittedly, such a Resistance must at times go into hiding underground and at other times strike fiercely. And we do sustain losses. But such losses are trivial compared to those suffered at Anorexia's hands. After all, it will even 'eat your smile for dessert'. What kind of life is it that Anorexia promises? To be a well-dressed Barbie-puppet, looking pretty? What do you make of her smiling as she goes about measuring herself up to perfection and torture?

What does Anti-Anorexia promise? Nothing but a place to stand and hold up a mirror for you to see Anorexia without its mask of benevolent solicitude. It is a longstanding tradition in the annals of punishment and torture that the executioner always keeps his face well hidden, is it not? From an anti-anorexic standpoint, Anorexia can no longer blindfold you or keep you in the dark. Now can you see what there is to see? Can you speak out against Anorexia because you have the language to do so? Can Anorexia conceal its intentions for you any longer? Are its promises turning to dusty betrayals?

If my experience in the League over the past 10 years is anything to go by, there will be struggle, but I suspect in and out of those very struggles, you will forge yourself for yourself. I can assure you there will be fun and celebration along the way. And one day you will decide for yourself to put your arms down. However, will you ever set your vigilance aside? After all, Anorexia is nowhere and everywhere: Anti-anorexia is merely somewhere.

Mary, we remain your sisters, your brothers, your comrades, and your friends-in-arms. We remain where we are, even if sometimes we must go underground, but we will never surrender. If I am any judge of Sharon and Warren, I believe that they would never surrender either. Never!!! To be one of us, there is no measurement, no examination and no assessment. Your suffering, which is so evident to all of us, is your welcome.

Welcome back even if you have to jump the hurdle of your 'examination'. We want you to know we abhor examinations. You are more than enough for Anti-anorexia!

I look forward to catching up with you next week.

David, on behalf of The Anti-Anorexia/Anti-Bulimia Leagues

Notes

1. David can be contacted c/- The Family Therapy Centre, 1 Garnet Rd, Westmere, Auckland, New Zealand.
2. By the 1990s, the requests for archival material had become too onerous and the means of its distribution too unwieldy and expensive. The archives themselves were growing at such a rate that they were starting to defy my means to even store them. From 1992 on, many League members had been urging me to compile the archives and make them available by way of a book. As such, this would have required the format of an encyclopaedia and I doubt if any publisher would have considered that a viable proposal. I could not imagine my way out of this, until I hit upon the idea of a conventional book (well, not really that conventional) that could be read for itself at the same time as serving as an orientation for a more complete archive, lodged on a website. Hypertext space is far more generous and less costly than textual (book) space. Otherwise, I should have been required to reduce, say, 5,000 pages down to 200 pages and, no matter how hard I tried, it was an utter impossibility. The integrity of the archives had to be maintained at all costs rather than an 'anti-anorexic' book of greatest hits. A manuscript is currently being prepared by Rick Maisel (Berkeley), myself and Alisa Borden (Los Angeles) for W.W. Norton, and is tentatively titled 'Anti-anorexia/anti-bulimia: Archives of Resistance'.

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