



PODS

Partners of Dissociative Survivors

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>>> PODS: Support for people whose partners, friends or family members suffer from a dissociative disorder

NEWSLETTER — FEB 2011

Rob's Report

It's been a busy 2011 so far and we're only 2 months in! On Saturday 19 February we had our first PODS workshop of the year, 'Living with Dissociation', and we hosted 68 people in Huntingdon. Our venue was bursting at the seams and we had had to turn away a number of people who wanted to come, so we're grateful therefore to already have several more venues and dates booked in for the rest of 2011:

- 9 April in Preston
- 18 June in Southampton
- 9 July in Bradford
- 17 September in Huntingdon
- 1 October in Hemel Hempstead

Full details of the workshops can be found on our website at www.pods-online.org.uk/events.html where you can also book online. They are principally aimed at survivors and partners/supporters, but counsellors, therapists and related professionals are also welcome. We've included a report of our February workshop on page 2 with some feedback from a couple of DID survivors who attended.

We are always on the lookout for suitable venues in other parts of the country. Ideally we require somewhere with two meeting rooms so that we can split into two groups for the last session of the day, as well as tea/coffee making facilities, and preferably a venue that is not likely to be too triggering for SRA survivors. Churches and church halls are often the most cost-effective and available venues, and these are fine as long as they are fairly bland or modern places. If you know of a venue in your vicinity that may be suitable, please do contact us. We would be especially interested in somewhere in the South West, Wales, and Birmingham/West Midlands.

We are also grappling at the moment with developing our organisational 'infrastructure' and hope to make some significant progress with becoming a charity over the next few months. We don't exactly enjoy the whole bureaucratic side of things, but are recognising that we have to develop a much more effective organisational structure in order to be able to carry the work forwards. We are also hoping to take on a fundraiser in order to apply for grants,

which requires that we have charity status first. So much of our time at the moment unfortunately is being siphoned off into this side of things ... but we're hoping that we're sowing in order to reap and the second half of the year we should be much more available to fulfil our objectives as PODS.

The helpline has continued to be busy, not just on Tuesday evenings (it is available from 6-8 pm) but at other times by appointment. To date over 225 people have contacted PODS directly, either by phone or email, to seek support or assistance. We know that this is a drop in the ocean but it is an indicator of the reality of the need. As well as continuing to help people individually in their recovery from the devastating effects of trauma, principally through supporting that person's partner/supporter, we also want to raise awareness in the counselling community. Many counsellors are only vaguely if at all aware of dissociative disorders but there seems to be a growing desire to find out more, as evidenced by the numbers of counsellors attending either our PODS workshops or the training days run by Carolyn as TASC. This is good news as unless more counsellors are able to work with and indeed recognise DID in the first place, the recovery options for DID survivors remains pitifully inadequate. Counselling organisations interested in in-house training might be interested in the workshops that Carolyn runs — for details go to www.tasc-online.org.uk/tasc-training.html.

One of the questions that we have been grappling with for some time—and expect that we will for a good while yet—is that of how people can access appropriate treatment. The debate of private therapy versus NHS funding is not an option for some people at all as they do not have the finances to fund the former themselves. We have written a brief article on this subject, which appears on page 3.

Please do get in touch if we can help you in any way and pass our details on to anyone else who might benefit.

Rob

If this newsletter has been forwarded to you from someone else and you would like to join our mailing list, please go to www.pods-online.org.uk/newsletter to sign up, or email us at info@pods-online.org.uk



Workshop Report — 19 February 2011: “Living with Dissociation”

Huntingdon is not particularly famous unless you're interested in Oliver Cromwell or Samuel Pepys, but not only is it home to PODS but it is also very accessible from various parts of the country, being located on the interchange of the A1 and A14 and being only 50 minutes from King's Cross. Perhaps that is why we attracted so many people to our second workshop here in the last 4 months ... or perhaps it's a sign of people's increasing awareness of dissociation and trauma and the desperation of some people to find anything that will help on their journey of recovery. Our workshops are aimed primarily at survivors and their partners/supporters, but we also advertise to counsellors and therapists and usually between a half and a third of our delegates fall into this latter camp.

A couple of DID survivors who attended the day have very kindly provided the following accounts:

Report by CB

Before attending the workshop I worried that the subject matter would mean that parts put in an appearance when I didn't want them to. On the day it turns out that I was right to be concerned; but I think we managed to cover it up, mostly.

Carolyn and Rob told their own story in basic terms to demonstrate how they have learned together about what is helpful and what is not. They used but explained jargon at a level that neither patronised nor confused, but brought an accessibility of resources all round. The information was relevant to my everyday life. It gave explanations for things we encounter and suggestions for handling them and moving forward towards stability and more control.

The speakers were easy to listen to even if the subject matter was a bit more tricky at times, but it was in no way gratuitous and they provided plenty of ideas and chances for grounding. The teaching was carefully diluted with humour and sensitivity whilst remaining relevant and useful. Everything that was talked about had significance for my life and I could relate to it all.

The use of time was very efficient and there was a lot crammed into a concentrated day. I was hungry for things that would have an impact on my quality of life, and came away not just satisfied but gorged. Questions I hadn't realised I had were answered and new questions have rapidly taken their place, so I want to get the next instalment as soon as possible. I realise that maybe I need to consolidate what I have found first and see how applying my learning can improve my life in daily practice.

I certainly came away with enough tools to try out, as I believe did everyone. It was aimed to provide resources for everyone; from the highly fragmented multiple to the very co-conscious, as well as bringing a wealth of insight for supporters. (I can't speak from the point of view of a therapist but the end of day question and answer session for that group went on way past chucking out time).

Report by Kitty

Having been to several other DID training days, I wondered if it would all be familiar information. As it turned out, much of the theory was new to me. It was really well researched and presented. The sound theory was related to real life as a DID by Carolyn, and to life as a partner/supporter by Rob. So I not only gained head knowledge but also the skills to apply it to my life.

I found all the information about how the brain works really useful. In particular it was helpful to learn how to reconnect to the thinking process when we are hyperaroused and swamped with emotions.

The other thing that powerfully impacted me was the need for self-acceptance. I realised that I have parts that I have been fighting against, and that I need to accept them. Only when they feel accepted and cared for can I realistically expect to be able to work with them, and gain some joint control over their domains. The things they needed to do to help me survive are not needed now, but they don't know that yet.



The Sixty-Four Billion Dollar Question: Unique Answers to the Question of Who Funds Therapy

If there's one thing I've realised over the last few years of working in the field of dissociative disorders, it's that no two survivors are the same. At any of the training events at which I'm speaking, I guarantee that at some point – usually at *several* points – I will use the word 'unique'. And that's a funny word in and of itself. Often it's loaded. It can be patronising, or bear a hidden but thoroughly ill-intentioned meaning of 'odd'. But I don't mean unique like that. I mean something very affirming, and something very intrinsic to understanding dissociative disorders.

I mean that you cannot herd up a group of 'DID people' or 'dissociative survivors' or whatever other collective phrase we invent, and spray-paint them as sheep, with markings on the side that say "DID – treat all the same".

I reckon working with DID must be at least a little bit scary. And when we're scared, we all have a tendency to become ever so slightly black-and-white about things, and we lose the tolerance to identify nuances and shades of grey. But if that is our approach to dissociative disorders, we risk being a source of retraumatisation or at least of dehumanisation, which I'd suggest is the core experience of abuse that led to us being dissociative in the first place.

People treated me as less than human – far, far less than human – and that treatment, that objectification, that scandalous disregard of my human rights, my feelings, my desires, my choices, my sense of self and dignity and respect ... that is what has led me to having this fractured, splintered series of mental/physical states that comprises being DID.

So we're on dangerous ground if we lose sight of the fact that the DID person in front of us is a unique human being whose sense of humanity needs to be restored.

And it is from that viewpoint that I consider the sixty-four-billion dollar question posed to us on a weekly, even a daily basis, at PODS: how do I get treatment?

In Utopia, it would be a simple trip to the empathic, well-informed GP who would refer you on immediately (preferably same day) to a consultant who is aware of power dynamics and how frightening and destabilising that can be for you, and who considers you to be the expert on you, and that he or she is there merely to guide and assist. Then, courtesy of the Utopian Health Service, you would be offered one, maybe two, sessions of suitable length per week with a local psychotherapist who is experienced in working with dissociative disorders (and doesn't take more than four weeks' holiday per year and is never sick), who is able to offer you a perfect blend of attachment-based individual psychotherapy utilising up-to-date resources, techniques and modalities such as Lifespan Integration and Sensorimotor Psychotherapy, and lasting as long as you need it. There would then perhaps be follow-up services – counselling or other support for your partner if you have one, a knowledgeable prescribing doctor who can help you with short-term crises or with areas of difficulty such as insomnia or pain, without giving you anything that will dull the limbic system to such an extent that you are unable to engage with therapy. And perhaps help with the costs of transport, perhaps a home help if you are physically disabled as a result of either the dissociation or the trauma itself, support for your children if you have any, dentists and opticians and family planning nurses and all sorts of NHS staff who are knowledgeable about dissociation and trauma and who work sensitively and effectively with you to help you access all aspects of healthcare without it being retraumatising.

Ah yes, Utopia.

If this were a TV programme, there would be a jolting screech and we would be transported suddenly and traumatically back into here and now by a patronising voiceover: "Er, no ... reality is the current state of knowledge and understanding today in this country, and in the NHS in your region."

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The Sixty-Four Billion Dollar Question: Unique Answers to the Question of Who Funds Therapy (continued)

And let's think for a moment about that issue of uniqueness. What I need from the NHS might be very different from someone else. At times in my life I have been in a wheelchair, but I have not been for some years now. But I know people with DID who are bed-bound, house-bound, wheelchair-bound. The Utopic vision of NHS healthcare provision would have to take into account the fact that some people with DID end up in wheelchairs, while others do not. I use that example because it is a visually obvious one, and if you have ever been in a wheelchair you will know how different the world seems from waist-height and you will realise that there are a lot of other issues for you as a DID wheelchair user than for a DID leg user.

Back to the big money question. How do we access treatment?

I have had very little help from the NHS. My doctor had never heard of DID but she didn't have a power thing going on and was willing to learn from me. That learning hasn't yet got as far as her being able to even *spell* dissociation, but she prescribes me whatever I ask for, and we seem to have a unique, respectful relationship. A few years ago as bank accounts were dwindling and the realisation set in that this was going to be a long-haul flight, we considered trying to get NHS funding to pay for my twice-weekly therapy which to date has set us back £10,000. And to cut a long story short, we didn't get very far with it. I was faced with a choice to either battle with my trauma – trauma which monopolised all my resources at the time just to get through each day – or battle with the NHS. And another aspect of life with DID arose at the same time, namely that of a police investigation against my perpetrators. I couldn't fight on all fronts. So the NHS battle was never fought.

But I am unique. I am in a unique relationship with my (two) therapists. I am in a unique relationship with my GP. I am in a unique position in terms of what is or isn't in my bank accounts. I am not saying that other people don't have *similar* circumstances,

but I have yet to meet anyone else who was abused *exactly* as I was within the *same* relational milieu, with the *same* outcomes, the *same* ensuing life story, the *same* partner/spouse, the *same* current life situation.

So when people ask us, "Should I try to get the NHS to fund my therapy?" what can we say? What is your unique position? What is your unique set of characteristics and traits and experiences and aspirations and difficulties, and what is the unique situation of your GP and your local NHS Primary Care Trust? What is the unique set of circumstances that is your battle, and are you able to marshal your resources towards the battle with the NHS?

I have carried a lot of guilt for paying for my own therapy. There are things that my husband and my kids have gone without because of it. Sometimes I feel that maybe I would feel more as if I am 'proper DID' (that elusive and nebulous status) if my condition were validated by a diagnosis by an NHS Consultant Psychiatrist. Sometimes I feel that I would feel better about myself if society in the form of the NHS took some responsibility for what happened to me and were putting it right. Sometimes I feel angry that 16 and 17 years olds can be paid £30 a week to stay in education (which will ultimately benefit them anyway) while I even have to pay for my prescriptions and receive absolutely no help at all from the Government for the effects of a multitude of crimes committed against me.

We listen in agony sometimes to the stories people tell us of their treatment within the NHS, of dehumanising assessments and dissociative care plans which serve only to destabilise them further and significantly lower their self-esteem. Many are the wounds of people who have fought that battle. I seethe with anger at the treatment of these dear people who are only trying to become human again and yet seem to be blamed and vilified for crimes committed *against* them. There are hoops to jump through, hoops and hoops and more hoops. But the last time I looked, that was an activity more



The Sixty-Four Billion Dollar Question: Unique Answers to the Question of Who Funds Therapy (continued)

appropriate for dogs at school fetes than traumatised people. What some people with years of experience in this field say – “If you can afford to steer clear of the NHS, do so” – seems to me to be wise advice indeed for these people.

But there are the people who cannot afford it and they have no choice but to battle. And some succeed. I cannot measure the cost to them, because after all they too are unique. When I hear of people after many long years securing treatment funded by the NHS at the Clinic for Dissociative Studies, I rejoice. Can I suggest to everyone who contacts us or asks us what to do that this is the right course of action? What of the issue of people who have therapy funded for 12 months and after 12 months they must ‘prove’ that they need it to continue? How does that leave the attachment to the therapist, with this Damocles’ sword of funding hanging over their heads? How can we really seek wellbeing if gaining some degree of it will potentially remove the support and the attachment relationship that we need in order for wellbeing to be a permanent and not a temporary state? I imagine the threat of ‘termination of provision of services’ would cause a huge sense of internal ambivalence. At least it would for me, but then again I am unique ... I suspect that 12 months of ambivalence is better than 12 months of nothing.

Is the NHS populated with power-crazy psychiatrists who refuse to believe in the existence of DID or (for those who accept its reality) refuse to talk to alters? Yes and no. Even people who work in the NHS are unique. I have met a great many of them who are wonderful people seeking to provide the very best therapeutic care to their patients. But they are unique too. I heard one story that DID exists in the eyes of the NHS in West Sussex, but not East Sussex. So Primary Care Trusts are unique too.

When I talk about how I am relieved that I have avoided the battle with the NHS, people tend to hear it one of two ways. There are those, many of whom email me afterwards, who are grateful for what they

see as the validation of the choice that they too have made. People may think that those who are paying for private therapy do so because they can afford it, but I’ve come to realise that many *cannot* afford it. And for some there is huge guilt at the sacrifices they are having to make in other areas of their life, especially when there are children involved and their self-funded therapy means that there are literally no presents at Christmas.

Then there are people who feel that I am somehow saying that it is wrong, or foolish, to pursue NHS funding. That is not at all what I am meaning. I applaud the courage and tenacity of people who have often fought for *years* to secure funding. Some do it for themselves, some do it for their partners or other family members. Every person that secures funding helps not only their own situation but also raises awareness in the NHS as a whole, and that is a laudable achievement for which everyone should be grateful. My caution about the NHS route is simply because unless people realise that it is going to be a battle, the wounds from it can be overwhelming, and my heart aches at the thought of anyone who has a trauma background similar to mine being wounded again in any way. I guess I just wish it did not have to be so. When people caution against the NHS route, it comes out of a desire to protect people from further hurt, not because it will inevitably be unsuccessful. People do fight and do manage to secure treatment, and often it is the people who give everything to this battle because they know it is their only option who are successful. There are distinct advantages to self-funding therapy, such as control and a degree of security and all it takes to start is a phone call and an appointment. But there are costs and disadvantages too.

So everyone is unique. Every person who works in the NHS is unique. Every Primary Care Trust, every mental health department, is unique. And everyone’s battle for treatment will be unique. That’s why the sixty four billion dollar question remains unanswered.

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Other Events

“Dissociation, Trauma and Time-Travelling ... or Living and Working with Dissociative Identity Disorder”

a joint Deep Release & TASC Training Day with Hazel Barton, Jane Potts & Carolyn Spring

Saturday 19 March 2011, 9.30 am — 5.00 pm
HOPE, Phoenix Centre, 9-27 Northway, Scarborough, YO11 1JH (£60.00 per person)
Saturday 10 September 2011, 9.30 am — 5.00 pm
Haven House, Hemel Hempstead, HP3 9AB (£50.00 per person)

Suitable for counsellors, therapists, survivors, partners, pastoral workers, Rape Crisis Centre staff, and anyone else interested or involved in the field of sexual abuse, trauma and dissociation

COURSE OVERVIEW

Carolyn Spring has Dissociative Identity Disorder as a result of early childhood extreme/ritual abuse. Using her story as a basis, and expanding out into the experiences from 'the other side' of two leading therapists, this training day will explore the mechanisms of dissociation and DID, the effect of trauma on the body and brain, the reality and therapeutic minefields of disorganised attachment, and how healing and recovery can be possible through appropriate therapeutic work.

The training will be led by Hazel Barton and Dr Jane Potts, two therapists experienced in the field of trauma and dissociation, as well as by Carolyn herself. It will be a fascinating day full of insights into both living and working with DID.

Please note that some content may be triggering for survivors but attempts will be made throughout the day to give advance warning

For further information or to book please go to www.tasc-online.org.uk/training.html.

“Campaign for the Recognition and Inclusion of Dissociation and Multiplicity”

a day-long event to raise awareness, share experiences and discover what all of us can do next

Organised by the Clinic for Dissociative Studies and the Paracelsus Trust

Saturday 12 March 2011

Resource Centre, 356 Holloway Road, London, N7 6PA — Cost £10.00

Topics covered will include:

- Living with a dissociative disorder
- Managing a career and developing creativity
- Getting the right diagnosis and treatment
- What's helpful and where to find support
- Where we go from here: challenging health services, the government and public perceptions

Presentations from survivors and those living with DID, and sessions chaired by representatives from key support groups including First Person Plural, PODS, TASC, RAINS, TAG, NAPAC and the Survivors' Trust.

Please note that Carolyn Spring will be speaking in the morning session, and Rob Spring will be speaking in the afternoon, and PODS will be also be manning a stall. Please come and say hi to us!

For details and to book (either online by Paypal/ credit/debit card or cheque) please go to www.pods-online.org.uk/did-conference.html



Useful Resources

Emergency DID Info Cards

To date we have now distributed over 1500 of our 'Emergency DID Information Cards' and they are still available free of charge to anyone who wants them.

They were produced in response to a request from a therapist whose client was ill-treated by healthcare staff following an emergency admission to A&E. None of the staff had heard of DID and even the duty psychiatrist was sceptical. It was therefore felt that it would be useful to have a card which carried some information about DID and which would be presented to health staff to inform them and to help 'authenticate' the condition.

The cards are double-sided business-card size so they fit easily into a purse or wallet. One side contains information on a "How to Help" basis, explaining the existence of alters and the realities of amnesia and disorientation, while the reverse side carries more technical information about DID from a medical perspective.

Go to www.pods-online.org.uk/resources.html for more details and to order, or email info@pods-online.org.uk letting us know your name, address and how many you would like.

TAG (Trauma and Abuse Group)



TAG is the Trauma and Abuse Group and is a charity with a membership open to survivors, counsellors, partners, healthcare professionals—just about anyone!

Membership is only £15.00 per year and the benefits include at least two copies per year of their journal/magazine *Interact* (edited by Carolyn Spring). This contains many articles of interest to both therapists and survivors/partners — each edition contains a range of contributions aimed at a wide readership. TAG members also receive quarterly members' e-newsletters which contains up-to-date details of training events, as well as further articles, book notices and reviews, and regular news items.

For further information, check out the TAG website, which also contains a wealth of information including articles and links to other organisations: www.tag-uk.net

FRONT

DID Emergency Information Card — How to Help

I have a condition known as Dissociative Identity Disorder. I am not 'mad' and nor am I attention-seeking or time-wasting. I have a history of severe childhood trauma and DID is a coping mechanism for this. DID is treatable via long-term individual psychotherapy.

I have different 'parts', 'alters' or 'personalities'. These may present as being of a different gender, age and developmental stage. We may be very frightened and traumatised and have difficulty distinguishing between the past and the present, so we may find it really hard to calm down. Please be careful about touching us and be gentle and patient. 'Alter personalities' may not be aware of what we have done (eg self-harm or attempted suicide) or where we are. We may be very disorientated and amnesic for what has just happened. Please try to understand our behaviours in the light of our past experiences.

This card is produced by PODS. For more information about DID and organisations that can help please go to our website at: www.pods-online.org.uk.



BACK

Information on DID — For Health Professionals

DID (formerly MPD): see DSM-IV TR section 300.14 and ICD10 section F44.

- complex form of Post Traumatic Stress Disorder caused by severe childhood trauma and abuse
- as in PTSD, may be severe dysregulation with intrusions such as flashbacks and avoidances eg phobia of touch; also episodes of overwhelming psychological distress, with amnesia, disorientation, marked somatisation
- patient/client may benefit from contacting therapist or supporter to stabilise
- "characterised by the presence of two or more distinct identities or personality states that recurrently take control of the individual's behaviour, accompanied by an inability to recall important personal information that is too extensive to be explained by ordinary forgetfulness" (DSM-IV TR)
- for further information go to <http://tinyurl.com/DIDinfo>



Useful Resources

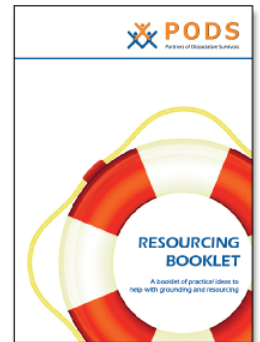
We now have a number of resources available on the PODS website at www.pods-online.org.uk/resources.html. These include:

PODS Resourcing Booklet

A booklet of practical ideas to help with grounding and resourcing.

"This booklet contains some ideas of things that will help you to turn down your triggered, panicking 'back brain' and get your sensible, thinking, problem-solving 'front brain' back online."

This booklet is available for free if you attend one of our workshop days. Alternatively you may purchase it for £2.50 inc P&P by Paypal or debit/credit card via the PODS website at www.pods-online.org.uk/resources.html.

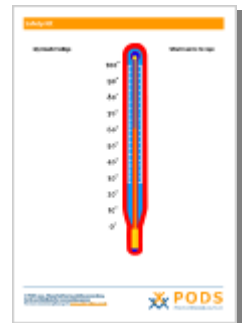


Grounding and Coping Resources — FREE downloads

PODS is currently putting together a series of resources to help dissociative survivors cope with triggers and everyday life.

At the moment we have two free resources available as downloadable PDFs:

'Emotional Thermometer' — this is a sheet to fill out either on your own, with a partner, or with a therapist, to identify what kinds of emotions you have on a 0-100 degrees scale. You list this sliding scale of emotions on one side of the thermometer, and on the other side, you identify what kinds of things you can do to cope when you're feeling that way.



'Alphabet of Emotions' — it's very common for survivors of abuse, including dissociative survivors, to struggle to put words to their feelings. This is a common symptom called 'alexithymia'. This 'Alphabet of Emotions' can help you to start identifying your feelings and increasing your emotional vocabulary. There is a sheet of possible emotions on one page with some fun cartoon characters, and on the next is a grid where you can start to build up your vocabulary of feelings. This can be very helpful when you get into a crisis so that even in your worst moments you can point at the sheet to communicate!



Go to www.pods-online.org.uk/resources.html to download them.