SURVIVING BETTER!

A Physical Health Information Pack for Survivors of Childhood Sexual Abuse

"From my own experience, I believe that we need to re-examine the way that child sexual abuse may affect many aspects of our health; we may gain control over a crucial aspect of our lives: health is empowerment, and ill health is continual disempowerment…
"Taking good care of myself, listening to my physical needs, is a way of defying the odds that were stacked against me, and beating them. It is a way of giving thanks that I am alive!"

—Julia Bridge, The Memory Bird

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By Sarah Nelson

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"I wasn't believed when I was ill, because I looked OK on the outside. I didn't feel I had a right to be here and breathe air. I was put down all the time, so I felt I had to put up with the pain. Because you weren't acknowledged…

You have to believe you are worth it before you can deal with your physical health: before you think you deserve better"

—Jane, In-care survivor

Sarah Nelson

Dr Sarah Nelson (Universities of Edinburgh and Dundee) has written and presented widely for decades on sexual abuse issues. Her research and publications include the voices of young survivors, critiques of current child protection systems, community prevention, organised abuse, media representations of abuse cases, and adult survivors' experiences of mental health services. She has also been a professional adviser to the Scottish Government and Scottish Parliament. Her book Tackling Child Sexual Abuse: Radical approaches to prevention, protection and support *(Policy Press) was published in 2016*

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Candice Schachter, principal investigator on the Sensitive Practice Project, and colleagues kindly allowed us to draw on their own work and to summarise a section of their 2009 *Handbook on Sensitive Practice for Health Care Practitioners: Lessons from Adult Survivors of Childhood Sexual Abuse*. She has asked when giving permission that we tell readers the Handbook is available to download free, from the Public Health Agency of Canada - National Clearinghouse on Family Violence: https://www.integration.samhsa.gov/clinical-practice/handbook-sensitivve-practices4healthcare.pdf

Sarah Nelson

Please note! We need to make clear that this booklet is not a substitute for medical care, and nothing in it should deter anyone from seeking medical help when they need it. In addition, chapter 10, on some therapies which survivors we work with have found helpful, is for information and discussion only. We are not advocating a particular therapy, nor suggesting that one is superior to another.

PHYSICAL HEALTH ISSUES FOR SURVIVORS OF SEXUAL ABUSE

Introduction

To clarify name changes which may prove confusing: our current generic title, Wellbeing Scotland, established in 2016, reflects the broadening of our organisation's work beyond its trauma remit. Open Secret remains the abuse and trauma service of Wellbeing Scotland. From now on in this booklet, we will refer to Open Secret or Open Secret of Wellbeing Scotland, since all the research and writing was done in relation to our trauma service.

This information booklet is for adult survivors of childhood sexual abuse, both women and men, who experience physical ill health. It is written in straightforward language, for a wide range of people. We hope it is also helpful for those who live with or work with survivors, who want to understand more about their health issues. It's the companion booklet to **Surviving Well: Good Practice for Health Professionals Working with Survivors of Childhood Sexual Abuse (2020 edition)**, also published by Wellbeing Scotland.

What we hope to achieve through this information booklet:

- To improve survivors' understanding and information about health problems they may face after childhood sexual abuse.
- To describe some research, and some theories, on why survivors of CSA are more at risk from these problems than non-abused people.
- To question theories which stigmatise survivors with physical ill-health, and to reduce self-blame and negative self-image.
- To enable survivors to feel more confident and knowledgeable in healthcare settings.
- To help them manage their own well-being.
- To describe some therapies which survivors we work with have found helpful.

We would especially like to encourage health professionals to display details of this information booklet, in a range of healthcare settings. It is informed by a range of research findings; by the practice experience of survivors and their support organisations; by the results of Open Secret's own Physical Health groupwork and Complementary Therapies projects; and by Dr Sarah Nelson's additional research at CRFR, University of Edinburgh, on physical health issues.

Why we produced this booklet

Wellbeing Scotland's own records from its Open Secret service reveal that 82% of their service users have had a significant physical health problem, which can affect many aspects of their daily lives and work. Kingdom Abuse Survivors' Project in Kirkcaldy, another major Scottish support project, put their own estimate at 75-80% of their service users. Severe and chronic pain, disability, gynae. problems, arthritic, respiratory and gastro-intestinal problems are only some of the conditions we see again and again.

Yet the mental health effects of childhood sexual abuse have received far more attention than the physical health effects. As a result, there is very little information available for survivors of abuse that isn't in medical, scientific or academic language. Often survivors already fear going for medical or dental tests, where treatments may feel unsafe or may trigger memories of abuse. Many survivors feel they don't deserve help and despise and try to ignore their own bodies. On top of this, many have had negative, off-putting experiences when they have sought medical help.

Stigma and prejudice

The pioneering physical health projects run at Open Secret, which resulted in survivors putting together recommendations for GPs and other health professionals in Surviving Well, revealed many examples of good professional practice, and many positive experiences. Unfortunately, they also revealed some attitudes and comments which made survivors feel stigmatised, dismissed or isolated. People could be viewed as hypochondriacs or 'heartsink patients' when they kept trying to find out why they had so many health problems.

Survivors' pain and disorders have regularly been considered 'psychosomatic' even before tests were done, or histories taken. Some theories paint survivors as overdependent and needy people. This poorly recognises their courage in enduring many years of pain, disability and uncertainty. Such attitudes only put survivors off from seeking help, or from attending preventive health checks.

We were greatly encouraged that the Royal College of GPs in Scotland warmly welcomed our Surviving Well booklet, and all the good-practice examples it highlighted for medical staff. We hope that in turn, survivors of childhood sexual abuse - some of whom, let's not forget, will work in healthcare themselves - will find this new booklet gives them information, understanding and confidence. Above all, we hope it will demonstrate that they are far from alone.

Summary

Chapter 1 describes the main physical conditions which survivors of childhood sexual abuse are found to suffer from more than non-abused people. These can be 'medically explained' or 'medically unexplained'.

Chapter 2 describes a wide range of possible reasons why survivors of sexual abuse might suffer physical ill health over the course of their lives.

Chapter 3 has direct quotes from survivors - about some of their experiences, about how they feel about their bodies after childhood abuse, and about how they feel when approaching healthcare settings.

Chapter 4 explains some influential theories about why survivors of abuse suffer from these health conditions, theories which have often stigmatised or dismissed them. They include 'somatisation', 'catastrophising' and 'fulfilment of dependency needs'. Some quotes from survivors illustrate the negative ways these have made them feel in healthcare settings.

The next three chapters set out several theories and research findings which we believe, from long experience of working with survivors, better explain their illness, pain and disability. These are:

Chapter 5 a) The neuro-biological effects of trauma, and b) trauma and dissociation.

Chapter 6 Direct impacts of sexual violence, including injury and infection.

Chapter 7 'Iatrogenic' conditions: how investigations and treatments can themselves sometimes cause problems.

Chapter 8: This describes good practice in sensitive care for survivors of CSA. It combines important work by authors in the field, and survivors' own comments about positive practice they received from health professionals.

Chapter 9 Advocacy Issues for survivors and their organisations

This explores some issues on which survivors and their support agencies have called for improvements in healthcare, or issues where they may want to see improvements in future. It includes some patients' rights issues, and training and information projects with direct input from survivors.

Chapter 10 considers the evaluation of Open Secret of Wellbeing Scotland's complementary therapies project.

The pack concludes with a list of references and useful publications, and some resources and websites which may prove helpful.

Chapter 1: Types of Ill-Health Among Survivors of Childhood Sexual Abuse

(See Appendix 1, References & useful reading, for details of the references and topics below and throughout this booklet. Appendix 1 also lists other research you may find useful.)

Childhood sexual abuse (CSA) remains a powerful predictor of health problems in adulthood – as numerous research studies have found.

One of the most striking studies has been Talbot et al.'s 2009 study of older patients. It found that CSA was associated with a higher burden of medical illness, worse physical functioning, poorer activities of daily living, and greater pain. The effect of severe CSA on impairment of daily living and pain was equivalent to adding a startling **20 years** of ageing to people's lives.

Larson et al.'s large 2005 study found that nearly 50% of sexually abused women with substance misuse and mental health problems reported serious physical illnesses. There are many more examples from research.

'Medically explained' conditions

According to such studies, child sexual abuse survivors have a greater risk than non-abused people of several conditions which have a medical explanation, including:

- Certain cancers;
- Diabetes;
- Auto-immune diseases;
- Coronary heart disease.

They are also at greater risk of conditions for which clear medical explanations do not exist at present, or where an organic cause hasn't been identified:

'Medically unexplained' conditions

- Irritable bowel syndrome (IBS) and other gastro-intestinal complaints;
- Chronic pain, including fibromyalgia, severe premenstrual pain and musculoskeletal pain;
- Respiratory conditions, wheezing and throat problems;
- Non-epileptic seizures;
- Chronic fatigue;

- Endometriosis.

Agencies supporting sexual abuse survivors have noticed a wide range of health problems in their service users.

The most common conditions reported by service users at the Open Secret service of Wellbeing Scotland over the years have been IBS, gynaecological disorders (often leading to hysterectomy), chronic pelvic pain, back pain, fibromyalgia, auto-immune disorders and chronic fatigue.

The most common conditions reported to Kingdom Abuse Survivors' Project (KASP) over the years have been:

Osteoarthritis; osteoporosis; diverticulitis (a digestive condition affecting the large intestine); irritable bowel syndrome; chronic back pain; fibromyalgia, joint pain and widespread body pain; emphysema; asthmatic conditions; COPD (chronic obstructive pulmonary disease); diabetes; urinary infections; migraines and gynaecological problems, which have often led to hysterectomy.

Unexpectedly serious findings

In our physical health research projects, we found service users experienced a wide range of health problems. The reason we list these below is to indicate the sheer extent, range and severity of health problems survivors faced. They often revealed these reluctantly and with embarrassment. The findings were unexpectedly serious and wide-ranging. Some people experienced extra physical violence along with the sexual abuse.

Total conditions reported from 23 female survivors from the Open Secret and KASP projects were:

IBS (almost universal); ulcerative colitis; chronic pain, fibromyalgia; non-epileptic seizures; hysterectomies; slipped disc; neck pain; migraines; repeated flu-like symptoms; severe back pain; arthritis; 'dead leg'; non-malignant tumours; asthma & respiratory problems; hypothyroidism; gynae. infections, pelvic inflammatory disease and prolapse of womb; breast abscesses; psoriasis; very painful periods; pelvic floor problems ; pain in genital & anal areas; anal tearing ; irregular periods; prolonged menstrual bleeding; fibroids; spondylitis (a type of arthritis affecting the spine) ; urinary infections and severe bladder problems; kidney pain/infections; incontinence; hidradenitis (a long-term skin disease); sinusitis; diverticulitis (a digestive disorder affecting the colon); spinal degeneration; inability to swallow properly; alopecia; chronic fatigue.

Most were unable to do paid work.

Among eight male survivors, the main conditions were IBS; chronic pain, including spinal pain and temporo-mandibular dysfunction; chronic fatigue; respiratory problems, and ear and kidney infections. One survivor has epilepsy, one sciatica, two noise-sensitivity and another has environmental sensitivity. The majority were unable to do paid work.

Another survivor of multiple abusers as a child and teenager experienced blackouts as a child, lifelong back pain, rectal pain, IBS, eczema, neuralgia in his face and jaw,

osteoarthritis and lung disease. Reflex gagging through oral abuse means he can't get false teeth fitted.

Most survivors in our projects had also experienced mental health problems following the abuse. These included anxiety, depression and PTSD with frequent nightmares; eating disorders, agoraphobia, and panic attacks or flashbacks, which had severely disrupted sleep. Sleep of course is a vital contributor to good health, to wellbeing and recovery. However, few had experienced a psychotic episode or a serious mental illness.

Having (or having had) mental ill health was the main reason why survivors very often found their wider health problems diagnosed rapidly as psychosomatic. Several people had been diagnosed with borderline personality disorder – a diagnosis which had negative effects on their relationships with health professionals.

What might some reasons be for such widespread ill-health among people who were sexually abused as children? Is there one possible reason, or many?

Chapter 2: What Can Cause Illness and Disability for Survivors of Sexual Abuse? A range of reasons for ill-health

There's no simple, single answer to the question: why might survivors of childhood sexual abuse experience physical ill-health? Here is a summary of some possible contributory reasons. Many of the issues will be discussed in more detail later in this booklet, and Appendix 1 gives examples of research.

- **Prolonged traumatic stress in childhood** causes changes in the body, especially in the autonomic nervous system, which make people more prone to ill health as adults - especially chronic pain, vulnerability to infections, and auto-immune conditions. This is the important and developing field of **neuro-biological research**.

- **Physical effects resulting from psychological effects of sexual abuse** are often overlooked**.** Yet consider how damaging to the body these can be: eating disorders and eating problems including anorexia, bulimia and binge-eating, repeated self-injury, suicide attempts, self-neglect during depression, or sheer inability to sleep, due to nightmares and flashbacks.

- **Childhood sexual injury, assault and sexually transmitted** infections can have long-term effects. These assaults are often repeated hundreds of times, over months or years, on the same areas of children's bodies, and extra physical violence may accompany them. These can be particularly relevant to some chronic pain, to gynae, anal, throat and urinary problems and infections.

- **Health effects of addiction to alcohol, illicit drugs and** tobacco are widely known. They include liver disease and life-threatening cancers such as lung cancer. Some survivors become addicted to substances - or have done earlier in life - in the attempt to 'self-medicate'. They have been trying to reduce or blot out distressing effects of trauma, such as flashbacks, nightmares and panic attacks. Often, too, abusers will have plied them with alcohol or drugs to make them compliant.

- **Survivors of CSA can experience the health risks faced by homeless people.**This can happen if for instance as teenagers they have run away from home or from care units to the streets, in order to escape abuse. Malnutrition, hypothermia, self-neglect, poor access to regular healthcare, infections and risks of assault are some of the dangers.

- **'Body-mind connections:'**

a) Periods of mental stress or anxiety

These may trigger, revive, worsen or be reflected in a physical condition. Such times may not always be negative in themselves. For instance a survivor may be committed

to bringing a case to court, and may feel very relieved that this is happening. But the experience can still be very stressful at the time.

b) **Dissociative experiences** affecting the body.

These complex processes are linked to past abusive experiences. Sudden bouts of extreme pain, or even a temporary paralysis, can arise. Symptoms may disappear and reappear. Triggers can include sudden reminders of the abuse. But they can also include being in a safe relationship for the first time - when people have found the care and support which helps them to confront past trauma.

- **Some psychiatric medications, especially long-term ones, and polypharmacy can bring health effects.**

Survivors can suffer side effects, occasionally serious ones, from some medications. They can suffer also from attempts at withdrawal. They may be prescribed several medications for a range of conditions, which can at times react with each other (polypharmacy).

- **Health problems can result from numerous tests, operations and sometimes inappropriate treatments.**

Survivors with several hard-to-diagnose complaints may have experienced repeated investigations, exploratory operations or surgeries. These can be done for very sincere reasons but can lead for instance to adhesions. They are ridges of scar tissue which link internal organs as after-effects of surgery or infections and can cause pain in movement. Sometimes inappropriate medication can also be given, if the diagnosis is not correct.

- **Survivors often fear and avoid preventive health checks.**

- Survivors of abuse may fear and avoid checkups which are important for everyone's good health, and for spotting problems early. Examples are dental checks, breast examinations, prostrate checks or smear tests. They avoid because the checks can trigger abuse memories and thus prove very distressing. Health professionals can do a great deal to make these important examinations feel safer, in dialogue with survivors' groups (see chapter 8, 'Sensitive practice - what research and survivors recommend').

The reasons for some conditions are likely to involve a mix of several factors above. At times unfortunately, the reasons may simply remain unclear…

Chapter 3: Survivors Speak Out

"It followed me round like a bad smell
Like the stone I couldn't find in my shoe.

That memory bird, who whispered in

My ear- now I thank her, for telling me".

(Janine Grice)

Here are the voices of some sexual abuse survivors from both Open Secret and KASP. They describe their difficult relationship with their own bodies. Do they reflect your own feelings, or not?

Being alienated from your body

"I'm aware of where every single part of my body is all the time. I never spontaneously moved in my life. I would wear any face deemed appropriate by my mother, but I would also position my body in certain ways, all the way through school. I had to think before I moved anything. My mind and body never felt connected. My body felt like a machine." (from Young, 1992)

"And [the amount of attention that I give to my body] ebbs and flows too, depending on where I'm at and how well I'm choosing to take care of my body. Which is a very difficult thing for me physically to do, because when you don't live there, it's just sort of a vehicle to get around". (from Schachter, 2009)

Hating or disliking your body for "betraying" you

As children, many survivors believed something about their bodies must have invited the abuse, especially if the perpetrators blamed them. This belief is reinforced if people enjoyed certain aspects of the abuse, such as special attention, or if they experienced an automatic physical arousal. Conflict between the need to seek help for a physical problem, and dislike - even hatred - of one's body can cause people to ignore their symptoms:

"I realised I believed my body had betrayed me, by having pleasurable feelings when my brothers were abusing me. Therefore I hated my body, and if it did anything I didn't want it to do, I would simply ignore it. And I did that to the point of nerve damage in my legs and a ruptured disc" (from Bass & Davis, 2008).

"Self-hatred has made it impossible at times for me to listen to myself or believe I am important enough to have health needs. Denial has made me simply cut off physical sensation, dismiss pain as 'being silly', and value self-neglect as proof that I was strong … I treated myself worse than any machine. … when I was 20, due to self-neglect I got a middle ear infection and was advised to have an operation. I ignored the advice … now more than 30 years and two operations later, it is an incurable and debilitating chronic condition.

"…When I was 48, I was lucky enough to find the therapy and the therapist that I needed. My therapist said 'I will always remember you as the child who didn't know that she had the right to feel pain'" (Bridge, from Malone et al., 1996)

Fear of being traumatised again

"…And the goop that they put on me for the ultrasound gave me flashbacks, nightmares, insomnia; I just couldn't deal with it" (from Schachter, 2009)

"This may be a person who's gone through something very traumatic …[who needs] some really safe technique … because otherwise you're going to have a certain segment of patients that are going to walk away feeling as though they've been abused all over again, quietly abused, just walking away and seeking another health care practitioner, just going through the cycle, again and again and again, and maybe not understanding why, maybe not knowing how to say it…" (from Schachter, 2009)

The effects of dissociation

"Personality-splitting – which I experience as a form of amnesia … has also caused havoc with (my) health needs: making me forget what I have experienced and said, when to take medicines and so on, and it has contributed to bad relations with doctors." (Julia Bridge, from Malone et al., 1996)

Fear of disclosure

Many survivors are reluctant to disclose their history of sexual abuse to a healthcare professional - and reluctant to answer "yes" if they are asked about it. They are afraid of being judged or disbelieved. In our own project, survivors made comments like:

"I'm afraid of the answer I might get - not being believed or looked down upon".

"I feel dirty to bring up the subject, in case I get judged".

"I'm frightened because of the fear of rejection".

As for men, 'real men' aren't supposed to be victims, nor to need extra help if they are. *"I feared if I told of history of abuse, they would think I was making things up and would be dismissive. So that I would feel humiliated, like a small boy again…"*

…So shame and self-blame make you think you don't deserve care

"One of the reasons why for a long time I didn't go [for medical help … quite frankly, I just didn't feel worthy … worthy of the care, the attention. I mean doctors are busy". (from Schachter, 2009)

Survivor, Open Secret: *"You don't want to bother people (at the surgery) - you don't want to be noticed - you feel really grateful at anything that's offered. I don't want to be a nuisance."*

"'Why didn't you 'phone for an ambulance?'" asked one puzzled doctor who visited the house when a survivor) was seriously ill. "You can stand the pain because you have to, because you've had it all your life. You feel you are not sick enough to call an ambulance" …

However, there is a saying "the body keeps the score" and survivors find they cannot eventually ignore the signals it sends out without a big cost to themselves:

Connecting You with Your Past

"My body is the only thing that puts me in touch with my past at all. I think that my body is speaking to me. The body will never be deceived: it will always be there to remind you … you can drug it, you can do whatever, but sooner or later you're going to have to pay your respects" (from Young, 1992).

In-Care Survivors: Extra Burdens

Survivors of the care system and institutions often faced both sexual abuse and physical assaults over many years, as well as removal from their families. Several service users of the In Care Survivors' Service reflect on this:

Rosemary: *"My abuse was both physical and sexual (in care, from aged four to ten). We were hit over the knuckles with a ruler … hit with a bamboo stick, with legs of tables … I got hit very badly on my hip side. Then down on your hands and knees scrubbing floors before you went to school … my hands, knees, hips are all terrible now … I have arthritis in my hips, arms, hands, and a trapped nerve in my hip. Then I was gang raped when I left care. I was walking the streets so it was (seen as?) my fault. … you are told by so many people that it's your fault, you lose all your confidence or the sense that you deserve help. I think differently now".*

"You have to believe you are worth it"

Jane*: "I was in care from age 3 to 18. … I was gang raped at 13, but was told 'your memory must be playing tricks'. But I've developed in character now, and not prepared to accept lupus is the predominant problem … attacking joints and healthy organs. Inside I am strong, but my body is failing. I also have COPD (chronic obstructive pulmonary disease) through heavy smoking in care - we all smoked heavily.*

"I have very mixed experience of healthcare. I wasn't believed when I was ill, because I looked OK on the outside. I didn't feel I had a right to be here and to breathe air. I was put down all the time, so I felt I had to put up with the pain. Because you weren't acknowledged…

"100 per cent, you have to believe you are worth it before you can deal with your physical health: before you think you deserve better. Addressing the abuse means a lot of pain, but it's life changing. Think of the money health and social services will save if children are brought up healthily, and the next generation will not tolerate what we tolerated - they will never regret spending the money!"

“Too young to have these conditions?”

Christine: *“I was in care from a very young age. I was also systematically abused at home … there were poor records, and these have been lost. … a nurse tried to drown me one time. Damage to my spine and neck was found in 2000. I have been diagnosed with epilepsy and lupus. As an adult I would pass out with the pain. I was told when young I was too young to have these ‘rheumatic’ conditions.*

“I became quite resilient as a young person and tried to hide it all up to about 2 years ago. I had high levels of shame because people were very judgmental. I would deliberately go for extreme sports. I pushed myself so hard in order to feel in control – to diminish the power this had over me - it led to total burnout.

“My war-paint goes on, my make-up, you get so good at hiding the abuse. You don’t know how to articulate the pain, because it’s never mattered (to other people). Who listens? Who is there to tell? You almost feel you don’t exist. Did I feel I had a right to be well? No, I was too busy trying to please … I thought I was a hypochondriac. You are predisposed to believe this. The way to deal with expectations is not to have any.

“*The records are destroyed, but my body may be a map! The body may reveal the truth, … if it could be proved, from the childhood trauma through to being diagnosed with this. What I have found inspirational, instead of lots of medications, is being involved with dance and music. And the support from wonderful people … you have to feel you deserve to be well first, before you can go for help to get better. I think feeling better mentally and physically has to go hand in hand.”*

“No idea what I had a right to feel”

Paul: *“I was physically and sexually abused at home from a young age and in and out of care. I was in two list D schools where I got physical restraint … My anxiety affects my breathing, my concentration and trying to get on with people. I get muscular pains and suffer from lack of sleep … and irregular sleep. Conflict with people makes everything worse. I have slashed my arms to try and make the pain go away.*

“When I was working. I made suicide attempts - I enjoyed the work, but the anxiety about how people would treat me affected me … I lost my job. I had no concept about whether the abuse was right or wrong, or what I had a right to feel. The pain for me was normal. I told people: ‘I can tolerate it, because it’s normal’”.

Do all the quotes from survivors in this chapter give the impression of hypochondriacs, attention-seekers or very needy, demanding people? Or do they instead come across as people who felt they “did not have the right to be well”? Those will be questions to consider in the discussion of stigmatising theories in the next chapter.

A Poem by Abigil Robinson:

"Being a 'survivor': what did I learn in order to survive?

To put other people's needs first/To make myself invisible/To blot out intolerable realities;

To efface myself/To merge with the identities of others/To become the occluded soul;

To internalise my anger, transforming it into fear and guilt/To cut off from my fear, sadness and self-love/To doubt myself/To doubt myself in relation to others/ To avoid intimacy;

To disconnect from and distrust my sexuality/To put myself down, to denigrate my life and my achievements/To act out of self-hatred and a desire to destroy myself.

(Robinson, from Malone et al., 1996)

Chapter 4: Theories About Physical Ill-Health which Stigmatise Survivors of Sexual Abuse

(See also Nelson et al., 2012 and Appendix 1, References and further reading)

The theories which have most influenced the way many medical staff have interpreted survivors' health problems have, unfortunately, contributed to disparaging attitudes by some staff. We are not suggesting that these theories have been constructed deliberately or wilfully. But their effect has been to make less credible both sexual abuse survivors, and people generally who experience mental ill health. You can decide how much sense the theories make for you. Here are three of the major ones.

Theory 1. The poor attachments and lack of care which many survivors of CSA suffered as children make them more dependent in later life. They are more likely to seek medical help, and to find comfort in a 'sick role'. They are said to achieve a 'secondary gain' from this.

This popular theory has it that lack of early care and attachment leads to needy, dependent patterns - where people seek out healthcare repeatedly in order to attract the care and comfort, they lacked but longed for as children. This is viewed as bringing CSA survivors a so-called secondary gain – the 'fulfilment of dependency needs'. It raises an image of rather weak clinging creatures, who at best deserve sympathy and compassion, and at worst become doctors' 'heartsink patients'.

This dependent image may fit a minority of sexual abuse survivors, those who have considerable and persisting problems of attachment and distrust. The problem is that it goes much against experience with the majority of survivors. As chapter 3 suggested, they are more likely to try and avoid healthcare settings unless it's really necessary; to find not gain but humiliation from experience of these settings; to ignore their body's needs; and to put up with pain and disability at their own cost.

Theory 2. Childhood sexual abuse may make people hyper-sensitive to pain. Due to their anxiety, depression or other mental ill health, they may magnify, 'catastrophise' or be pre-occupied with pain and other physical symptoms.

The problem with this theory is that experimental pain studies have shown sexually abused people tend to have higher, *not* lower, pain thresholds than non-abused people. This might perhaps be because, due to childhood experiences of pain, they have learned techniques to dissociate or 'block it out'.

Some survivors in our projects found doctors and mental health professionals assuming that they amplified their pain, even when the evidence in their medical records suggested the opposite!

Laura: *"My mother and I were told by a dentist at age eight that I had surprisingly high pain threshold. But in my late teens I was told by a psychiatrist, when he had learned about my sexual abuse, that I had a low pain threshold!"*

Theory 3. 'Somatisation' and 'somatoform disorders'

This is the influential theory of **somatisation** (see Lipowski, 1988), which developed from earlier concepts of 'conversion' symptoms. The theory has it that emotional stress translates into – or is expressed by - bodily symptoms.

Few people would disagree that interconnections between our bodies and minds clearly exist – especially in times of stress. We have all experienced them, such as being sick and/or unable to sleep before taking an exam or driving test, or before having to speak in public. These inter-connections are also, of course, very important in holistic medicine, all over the world.

Accepting the links, which can be complex, is not the problem. The problem for survivors of sexual abuse has come when it's automatically assumed (without proper investigation or informed knowledge, in a simplistic way) that their mental state must lie behind their physical symptoms.

Numerous experiences by survivors suggested some medical professionals have jumped to the assumption of 'somatisation' before even conducting tests. This emerged as by far the biggest issue for survivors in Open Secret of Wellbeing Scotland's own research projects:

'All in the mind'?

Laura: *"Doctors all assume its emotional distress. But surely it's not normal to have so much pain that you can't sleep. I have pain in my hips, neck, fingers, feet, toes, my joints … I have had headaches regularly for years … I had IBS for a long time also, as a teenager especially. I have bad periods and they can last up to 2 weeks".*

Carol A: *"When I was 16 and suffering terrible stomach pains, I was in hospital and the nurses' attitudes towards me changed when they saw my records (revealing CSA). They said, 'we would like you to see our psychological doctor … we know your pain seems real, but it's strange the way the mind works' … and they hadn't even done my tests!"*

Carol B: *“I overheard doctors in hospital saying to each other ‘she’s got mental health problems, I don’t know if there’s anything wrong with her or not’. They do treat you differently – they think you’re mentally damaged. When they find out you’ve been abused, they think it’s all in your head”.*

There has also been gender bias in the way ‘somatisation’ has been applied. Females (traditionally seen as more emotional, or even hysterical) are ten times more likely to receive this label than males are.

“Given the looseness of definitions, it is a short step to diagnosing any patients with unexplained symptoms as having a somatoform disorder … the verb ‘to somatise’ and the noun ‘somatiser’ are unusual in the vocabulary of medicine because they imply that patients are performing a deleterious action on their own bodies … only the stigmatizing term ‘somatiser’ implies that patients are the authors of their own bodily suffering” (McWhinney et al., 1997).

Uncritical use of ‘somatisation’ has been criticised by some medical professionals themselves. Nelson et al. (2012) considered all its difficulties in their wide-ranging review of the research literature. In particular it is not clear why anyone should assume that the sometimes extreme sexual violence suffered by victims of CSA would have only a psychological effect, which then translates back into a physical symptom!

Survivors in our projects said they wanted health professionals to approach the possible causes for their symptoms just as open-mindedly as they would with any other patient. Of course, there are indeed emotional influences on health problems.
But these should not be assumed in advance, without evidence, as the primary cause.

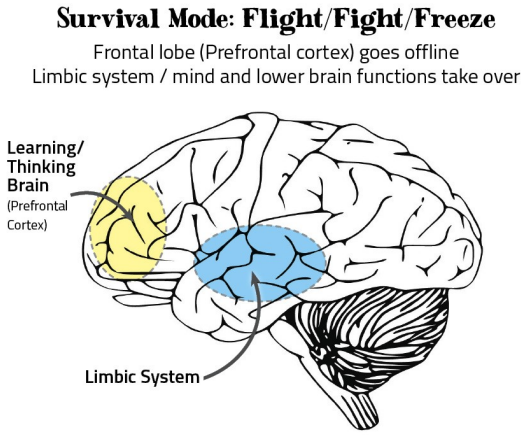
Chapter 5: The Impact of Neurobiological Change and Dissociation

a) Neurobiology and Stress

"I believe that another direct effect of my abuse was hypothyroidism. As a child at home, every day was a crisis, and my metabolism adjusted accordingly. When I left home and began life in an environment free from constant anxiety and violence, the lack of stimulation cause a hypothyroid crisis; and I have had a struggle ever since with metabolic imbalance. I also have chronic sarcoidosis, an (inflammatory) auto-immune disease that seems particularly common among survivors of child sexual abuse … it was about 8 to 10 years before it was discovered through the vigilance and persistence of a GP who … believed in my right to be well, more than I was able to myself".

In this quote, Julia Bridge - in that excellent book by survivors, *The Memory Bird* (Malone et al, 1996) - refers to an influence on her under-active thyroid and her autoimmune conditions which has been much-researched in recent years. It concerns the effects on the body of extreme stress, trauma and constant crisis in childhood.

Faced with threat, danger and extreme fear, people usually have a 'fight or flight' response. This response galvanises all our available bio-chemical resources to tackle or avoid the threat. But for sexually abused children, they can often neither fight nor escape the situation. With the continuing threat of further abuse, their hyper-vigilant state becomes permanent instead of calming down after a crisis, in the way our bodies intend.



Flooding the system

Such survivors risk being constantly in physical and psychological discomfort due to the adrenaline and cortisol flooding their system. These states can result in chronic anxiety, physical distress and disrupted concentration. The digestive system is affected, the muscles are tense, the heart rate is increased and blood sugar levels can be disrupted.

Thus, severe stress and ill treatment in early years of life can produce a cascade of neuro-biological events which especially affect the hypothalamic- pituitary-adrenal (HPA) axis. These effects have been linked with endocrine, auto-immune and metabolic disorders.

Both high and low levels of cortisol have damaging effects. Cortisol is needed for many processes in our bodies, including our glucose levels, protein synthesis, our thyroid and immune functions. If proteins are not properly broken down, the body can see them as foreign. The immune system attacks them, bringing auto-immune disorders.
Flooding with cortisol can also that mean the body fails later to produce enough. When this happens, people are more vulnerable to viral infections and thyroid deficiency.

New technologies, new understandings

Many health problems, including chronic fatigue syndrome, fibromyalgia, some autoimmune disorders, pre-term labour and chronic pain syndromes can now be related in some cases to childhood maltreatment.

Thomson and Khan (2008) say it is very important not to label such disruptions to the system as "psychosomatic, functional illness or hypochondriasis". They argue that real and measurable physiological disruption is an inevitable result of chronic stress. Any implication that it is "all in the mind", they say, does a disservice to the person, and is likely to increase their stress.

In order to help CSA survivors, the challenge is to identify which of their health conditions reflect these neurobiological changes, and to discover which treatments and therapies might alleviate these.

That needs to include listening to survivors themselves, some of whom have campaigned vigorously and tirelessly for more effective treatments. Leading examples in Scotland are Sandra Whyte and her colleagues, in their petition to the Scottish Parliament in relation to more effective treatments for endocrine disorders (Whyte et al., 2012).

b) Dissociation

"The trauma was so severe, I did what many children do in order to survive. I split, or to use the psychiatric word, I disassociated. I split into what I call a 'day child' and a 'night child.'"

For years, Marilyn Van Derbur, a former Miss America, poured herself into overachieving as a 'day child' and teenager.
https://www.youtube.com/watch?v=ALEfE3rNCqI

But from her 20s onwards she slowly began to come to grips with the sexual abuse she suffered from her father, in a painstaking recovery that would last decades. When Van Derbur turned 40, she began to experience a strange physical paralysis that continued, on and off, for 12 years: "My body functions would slow, my pulse rate would drop into the 40s, and I would just lie there unable to move. I thought I'd die". Doctors were unable to find any reason for her symptoms.

Her daughter was then turning five years old, and she suddenly realised this was the age when her own assaults began. Her daughter's age had begun to trigger the memories and feelings. *"I used every ounce of energy to repress these totally*

unacceptable memories and feelings, and the result was physical paralysis, but it would be years before I would make the connection."

What is somatoform dissociation?

Many survivors have experienced baffling pains and symptoms, like the temporary paralysis of a limb, long after they were hurt as children. Symptoms can sometimes be severe, sudden and dramatic; they may disappear later. Some survivors for instance have woken up with waves of knife-like anal and genital pain, an unbearably painful throat, or other examples. Yet there is no obvious medical reason for these alarming symptoms.

We often hear these described as memories stored within the body, or 'body memories' – that is what they can feel like to survivors - although medical professionals tend to see this term as unscientific. Research on **dissociation after trauma** sheds greater light on these complex experiences.

Dissociation is usually thought of as being about the mind - about 'spacing out', about disruptions of memory, consciousness and people's sense of identity. It's a very complex defence mechanism which protects children from the worst effects of abuse at the time, but unfortunately it can continue into adulthood with less positive results.

Most survivors of CSA have experienced dissociation to some degree, after they used it as children to 'space out' during the abuse itself, or to pretend they were outside their bodies - such as looking down from the ceiling - when it was happening. Some survivors also experience during therapy a temporary regression, where they go back to the original abuse situation (such as becoming a terrified child again, cowering in a corner). Yet they don't recall this afterwards. In an extreme form, among a minority of seriously abused people, they can experience dissociative identity disorder, which used to be called multiple personality disorder.

Bodily symptoms too

But especially through the research and insights of Onno van der Hart, Ellert Nijenhuis and colleagues, (2004) it's now more and more recognised that dissociation can relate not just to the mind but also to bodily functions, movements and experiences. It can do this in both humans and animals.

Somatoform dissociation, as it's called, features effects such as 'freezing'- the familiar 'rabbit caught in headlights' scenario. In both humans and animals, when neither fight nor flight is possible, this freezing mechanism floods the body with anaesthesia and pain relief. Acute pain is felt only afterwards, if survival is achieved. For some abused people, this pain can happen many years after violent sexual assaults.

Having permission to remember, and to feel?

Surges in symptoms often happen when adult survivors are finally in a safe, supportive relationship. This may sound strange, but the reason seems to be that it finally feels safe to allow unbearable memories and feelings to surface and be dealt with. Symptoms can also appear when certain triggers of the abuse happen - or when sensitive, therapeutic bodywork reconnects survivors with their alienated bodies.

Rebecca Mott, a child sexual abuse survivor who went on to experience a great deal of sexual violence in prostitution, has spoken of feeling extreme genital and anal pain, some

years after escaping prostitution. She makes a thought-provoking point about this kind of experience. “I was never allowed to show that I was in pain during the violence I suffered. I was always meant to be smiling and enjoying it”. (Mott, personal interview 2014; also see https://rebeccamott.net/) She had to deny the pain, both to herself and to others at the time. Only later was she allowed to feel it.

Some researchers and clinicians (such as Bowman, 1993) believe that actual re-enactment of assaults can be expressed through bodily disorders. For example that the thrusting movements, the distress and crying often seen in non-epileptic seizures may be re-enactments of sexual assault, in some sexually abused patients.

The need for support

Pain and disability resulting from dissociative experiences are areas where trauma counselling can prove helpful. Survivors might welcome a lot of support when they address difficult or distressing memories. Therapeutic work with dissociation can lead to people recognising particular forms of abuse and ill-treatment which happened to them, which they were not aware of. Recognition and understanding can come as a relief, if people have had years of feeling baffled and confused about these symptoms. But of course the knowledge discovered can still be distressing. Therefore, it would be important for you to think about finding good support while you are doing this work.

In order to help CSA survivors, the challenge for professionals and researchers is to identify better which of their symptoms and disorders may reflect somatoform dissociation; and to discover more about which treatments and therapies might alleviate their suffering, and prevent the symptoms being repeated.

Chapter 6: Effects on the Body of Physical and Sexual Violence: Injuries and Infections

Many survivors experienced sexual assaults as children - for months or years at a time- on the same parts of their bodies. Many also experienced extra violence, such as being punched, beaten or tied up. These will leave effects on their bodies, as well as on their emotional well-being.

Survivors often feel ashamed, humiliated or embarrassed to tell medical staff about things that were done to them. But it can be helpful to consider if some of the pain or ill-health you experience could be linked to particular past assaults. It can make better sense of some baffling conditions, it can reduce your self-blame, and it can reassure you that it's absolutely normal for your body to react after repeated violence.

You can choose whether you want to tell a health professional the details of what happened to you, or to keep these private. However, exploring some possible links may make it easier to find more appropriate check-ups, treatments and therapies.

Please note! We want to be honest in this information booklet, even about things that are difficult to speak about, because there has been so much silencing around the effects of sexual abuse; and because we know from talking to survivors that many assaults are violent and sadistic. But this means some of the discussion below could be triggering. So if you are not feeling in a good place at the moment, leave it for another time. Or if you're worried that you might be triggered, please make sure that there's somebody around to support you.

When injuries and infections go unattended

We all have childhood accidents and illnesses, but normally a parent or carer will take the child for medical help, and the effects will be reduced. This may not happen with sexual abuse and deliberate violence, and so the longer-term effects can be greater. Reasons include:

- Abusers will often try to conceal what they've done, neglect the child or fail to take her/him for medical treatment. This can result in poorly-healed fractures, poorly-healed injuries or untreated sexually-transmitted infections. These can lead to pain, fertility problems and to conditions like pelvic inflammatory disease.
- Assaults might be repeated hundreds of times on similar areas of the body, over months or years.
- Penetrative assaults on the small bodies of children before they reach puberty can cause internal damage.

What actually happened is not traced…

One unusual thing about medical diagnosis in survivors of sexual abuse is that what actually happened to people's bodies is rarely traced. When you think about it, this is very unlike the situation after – say - sports injuries or car accidents, when the history may be clearly recorded. In sports and exercise medicine, a complete history is taken to help diagnosis and treatment. Very detailed assessments are made of soft tissue lesions and chronic over-use injuries, and how these happened is explored. Specialist treatments are available. In orthopaedics, for broken bones we find a good deal of attention to diagnosis, treatment, rehabilitation, exercise, therapy and medications.

If the histories of injuries are not traced, it's much more difficult to reach an accurate diagnosis…

Assaults affect several functions of the body

Perpetrators assault their victims in many different parts of the body. However, regions most often targeted for repeated sexual assaults are the **genital areas, anal areas, and mouth and throat areas**. Sack et al. (2007) are (surprisingly rare) examples of researchers who link the body's symptoms to the actual sites of sexual assault.

An important point to remember is that the genital, urinary and reproductive areas are all very close together, involving your sexual sensations, your reproductive system, and your regular functions of going to the toilet. Organs in the throat area also cluster together. These include voice-box (larynx), pharynx, trachea (windpipe) and oesophagus, which help you to breathe, speak, swallow and digest food.

Thus, damage to one important part readily affects another important part of your body.

Research studies confirm this multiple damage. For example, Beck et al. (2009) found that female patients with an abuse history had "significantly more complaints in urinary, defecation and sexual function" compared with non-abused people. Devroede (1999) also describes how the pelvic floor is closely involved with the urologic, genital and intestinal tract, so all these dysfunctions can overlap. Thus the term 'chronic pelvic pain'

- known to have strong associations with a sexual abuse history - can cover many sources of pain in that general area of the body.

These overlaps might give one practical explanation of why many survivors struggle with having many things wrong at the same time - and why they often get branded 'hypochondriacs' or 'somatisers'!

Also very important is that the division of adult medicine into many separate specialisms (like ear nose and throat, or gynaecology) makes it genuinely hard for doctors to see the whole picture. Survivors might thus go round different consultants in frustrating circles, without the jigsaw pieces being joined together.

Areas of the body most often assaulted

1) The genital, urinary and reproductive areas

Although these are more often considered a female issue, males also suffer assaults on these areas. For girls this can include repeated penetration of the vagina not just by a penis, hand or fingers but by objects. These assaults also feature in creating online child abuse images for particular abusive or sadistic audiences. Males have also suffered attacks, on the penis and scrotum areas (see for instance Hobbs and Osman, 2007).

These assaults can inflict cuts, burns, repeated bruising and soft tissue injuries, internal damage, scarring, unwanted pregnancy or sexually transmitted infections. If medical staff don't consider assaults, they won't look for possible effects. Often overlooked, too, is the fact that perpetrators can be unwashed and dirty, raising the risk of infections.

Gynaecological problems are extremely common in women survivors. Support agencies (including Open Secret of Wellbeing Scotland and KASP) find high rates of hysterectomies among survivors. Fertility problems, ectopic pregnancies and endometriosis are also quite common. Such problems have emotional effects too - they can affect a survivor's whole sense of identity as a woman and a mother.

Urinary problems

Peters et al. (2008) studied women with interstitial cystitis and painful bladder syndrome. They found that 58% reported child sexual abuse, 65% physical abuse, and 43% domestic violence. Most had had pain for five years or more. More than a quarter had caesarean births, more than three-quarters had a miscarriage, stillbirth or abortion. Nearly half of the women had had a hysterectomy. Deep pain with sex was reported by 77%. More than 40 % had IBS and stress urinary incontinence. They reported on average four pelvic surgeries. The researchers concluded that these patients were "in desperate need of care".

Vulvodynia in adulthood - pain or discomfort at the entrance to the vagina - has been strongly associated with sexual and physical abuse as a child. Vulvodynia can cause hyper-sensitivity to clothing or touch, and even limit simple activities like sitting and walking.

2) Anal damage: similar issues?

Anismus is a failure of the pelvic floor muscles to relax when people try to 'poo'. The sphincter contracts in the opposite way to normal. It's sometimes called 'spastic dysfunction of the anus'. Leroi et al. (1995) studied 40 women whose lower genitourinary disorders had been diagnosed as functional - that is, without any obvious

organic cause. All, it turned out, had experienced sexual abuse. In his research study, he found anismus in 39 of these 40 women, but in only six of 20 healthy controls.

Engel et al. (1995) found that in both men and women, anal penetration can cause permanent structural and sphincter damage. All the patients in this study had evidence of disruption to their internal sphincter.

3) Mouth and throat areas: the nature of oral sexual abuse

Very many survivors, both women and men, have experienced oral sexual abuse. For perpetrators, it's less likely to be detected - for instance it doesn't bring a risk of pregnancy, it may not leave outward signs, and it's easier to inflict on small bodies. People often feel ashamed and embarrassed to talk about it to a health professional, even though it's so common. This may contribute to a lack of awareness, in health services, of this form of abuse.

Repeated oral abuse that involves penetration can affect the throat and gullet areas as well as the mouth and teeth, and also the jaw when the mouth is being forced open. Oral abuse can cause panic and difficulty in breathing. It can affect the vocal cords as well as the ability to swallow. One woman recalled:

"Your throat is incredibly painful. I couldn't eat for days, or even drink without great pain. I couldn't talk for days either. My whole ''voice box' felt swollen. Your gagging reflex goes haywire. Afterwards, as a child, I used to scrub the inside of my mouth; I even tried to scrub the back of my throat." (Nelson, 2002)

4) Disorders of the throat, oesophagus, mouth and jaw

A lot of conditions relating to the throat area, vocal cords and oesophagus have been considered psychosomatic, or simply baffling. We don't know if they are psychosomatic (certainly, if distressing memories of abuse are triggered in later life, this might cause symptoms to reappear). But there's also a possibility of physical damage through oral abuse.

For instance, in paradoxical vocal cord dysfunction (PVCD) the vocal cords close when people breathe in (reversing normal function). This causes noisy, wheezy breathing called 'stridor'. It's been seen as psychosomatic and has attracted quite prejudicial names, like hysterical croups and Munchausen's stridor. Yet a sexual abuse history has been identified in PVCD patients in several studies, including Brown et al. (1988).

Temporomandibular disorder (TMD) or temporomandibular joint disorder (TMJ) affects the 'chewing' muscles, and the joints between the lower jaw and the base of the skull. It can cause much pain. It's often considered psychosomatic, though this is controversial. The American Dental Association for instance reckons the great majority of TMJ problems are caused physically, for instance by a blow to the jaw or a whiplash

injury. They add that repeatedly opening the mouth too wide can also cause TMJ. If your mouth is forced open for oral abuse, ligaments may be torn.

Is telling too difficult?

We are not qualified to make any definite judgments about the root causes of these often-painful mouth, throat and jaw conditions. (Nor indeed about the other conditions we discuss in this chapter). But if you suffer any of these and if you experienced oral abuse, you can think about whether you would feel able to talk to a specialist about possible damage or infection, which could be checked.

Would even giving general details face-to-face feel too difficult, however? If so, perhaps survivors and their support agencies could help medical professionals to devise a sensitive online questionnaire. Alternatively, they might wish to call for trained specialist nurses to be available, to whom survivors could talk*? (See Advocacy Issues, chapter 9).*

Sensitive means of telling might help, as well, after self-harm, which often feels shameful to talk about too. There are many different reasons for self-harm, which can of course cause health problems. But as one quote above shows, people may feel particularly disgusted and polluted by what abusers have done to them. They may then try to clean those parts of their bodies repeatedly afterwards, with damaging cleaning agents. For instance by putting bleach down the throat or in the 'back passage', after an assault. These are often interpreted as bizarre, senseless acts of self-harm, when they are desperate acts of understandable disgust.

5) Chronic pain

Chronic pain is one of the most common of all physical health problems in adult survivors of sexual abuse. It's tremendously wearying, and understandably it can bring a sense of depression and exhaustion.

Far more understanding is now evolving about how trauma in childhood can affect the central nervous system, producing heightened pain in many areas of the body later. *(See our discussion of neurobiology in chapter 5.)*

There are additional reasons why many survivors might be left with a legacy of pain – especially if extra physical violence accompanied the sexual assaults.

Some survivors were tied down, perhaps experiencing burns from rope or twine. Some sadistic abusers like to inflict pain deliberately, by burning, cutting or beating their victims, or giving them electric shocks. But even sexual abuse without overt violence has involved, for example, many children having a heavy man's weight repeatedly on their back or chest; or having their necks or hips put into unnatural positions.

CSA survivors have disproportionate rates of fibromyalgia (compared with non-abused people), experiencing pain at sites throughout their bodies. Neurobiology will be influential, but an extra insight may come from whiplash research, given how often survivors describe having their necks pulled into unnatural positions as children, e.g.: Laura: *"He would put me across his lap on a bed… then he would bend your head right*

back, so if anyone did come in, he could pretend he was tickling me."

Writing on fibromyalgia, Donald Liebell (2009) explains that that the greatest concentration of nerve connections in the human body is in the upper neck. Misalignment can lead to nerve compression, affecting the whole nervous system. The great majority of his patients were found to have a neck injury, often many years before the onset of their symptoms.

Again, repeated investigations and operations to try and discover what could be wrong with a patient leads to the increased production of **adhesions**. These are ridges of scar tissue which link internal organs as after-effects of surgery, and they can cause pain in movement. (See chapter 7 for more detail).

In conclusion…

This chapter has raised a major problem for society as a whole. If these serious injuries and assaults are not considered, not only might physical ill -health in survivors be misdiagnosed: the seriousness of sexual brutality against children in our society continues to be concealed.

Chapter 7: Iatrogenic Conditions

…What are they?

'Iatrogenic' refers to a physical or mental health problem which is caused by diagnostic procedures, investigations or treatments, or by the healthcare environment itself (e.g. exposure to toxins). It's important to stress that this does not necessarily mean there has been poor, uncaring or incompetent treatment. Rather, it refers to unfortunate effects which medical interventions can at times produce.

Why might these prove a particular problem for sexual abuse survivors?

1) Polypharmacy:

Adult survivors often face a range of both physical and mental health problems. They may have done so for years, or even decades. Thus, there's a risk that symptoms have been treated separately, with a growing number of different medications. That can lead to some negative effects.

Polypharmacy involves the current use of multiple medications. These will be necessary for some people and will constitute best care for them. However, polypharmacy is also linked with prescribing too many, or unnecessary, medicines at dosages or frequencies higher than are needed - with a range of unfortunate side effects.

Negative effects of polypharmacy, and serious worries about it, emerged as major concerns for the physical health project groups at the Open Secret of Wellbeing Scotland service. The project recorded the medications that survivors were taking and found that some people took as many as 13. Survivors' main concerns were:

- The amounts being prescribed;
- The addictive nature of analgesics used to relieve serious chronic pain;
- Concerns that some people were prescribed medications which were not recommended to be taken together. This could increase side effects;
- Worries about how far they could question their doctors' decisions;
- Getting used to the drugs meant their effectiveness diminished, yet side effects remained. For some analgesics, side effects included anxiety states similar to those which already afflicted the survivors;

- When severe withdrawal symptoms happened, these added to the stress of trying to cope with daily pain levels, and life in general;

- With tricyclic anti-depressants, weight gain was rapid, causing distress and a sense of futility. Diet and exercise were seen as the only way to counteract this, yet they had little effect.

In conclusion, it was no longer clear for some people if their health conditions were independent, or were the side effects of multiple medications.

2) Repeated investigations:

Another reason for the risk of 'iatrogenic' health problems in adult survivors is that they often experience conditions which are baffling and very difficult to diagnose. In the repeated, sincere effort to find what is wrong, they may be sent to many different medical specialisms. That can mean repeated examinations, tests, even surgeries.

For instance, Arnold et al. (1990) studied the case histories of seven psychiatric patients who were sexually abused as children, and had a history of medical or surgical interventions. Although they were only in their 20s or 30s, they had had an average of 18 contacts with non-psychiatric consultant teams,
and an average of eight operations, few of which identified the problems. Their many symptoms led to investigations and interventions in gynaecology, obstetrics, gastroenterology, urology, rheumatology, haematology, orthopaedics, neurology and neuropsychiatry. Their history of CSA was recognised only later.

Surgical interventions will always involve some level of risk, especially repeated surgeries. Multiple surgeries can lead for instance to adhesions.

Adhesions are scar tissues which can make tissues or organs inside the body stick together. They can be caused by infection or inflammation, but also by surgeries and operations, especially in the abdomen and pelvic areas. They can cause problems such as abdominal pain, bowel obstruction or infertility.

Some adhesions may cause pain by restricting the mobility of mobile organs in the abdomen/pelvic cavity, e.g. the bowel and ovaries. Nerve endings may become trapped as adhesions develop. Surgery involving the ovaries, endometriosis, the fallopian tubes, or fibroids can result in adhesions being formed. Adhesions can reduce the capacity and emptying of the bladder, causing pain and frequency - which can be mistaken for cystitis.

Scar tissue can result in the ovaries being displaced or in a blockage of the fallopian tubes, sometimes leading to infertility. It's notable that these are all parts of the body where - support agencies have repeatedly found - female survivors (and males, in relation to bowel disorders) have experienced problems and chronic pain.

Surgery to disconnect adhesions is currently the only way to treat them. All surgery, however, carries a risk of creating further adhesions - although this is less likely with modern keyhole surgery.

A warning…

It's important to say that these problems about multiple investigations do <u>not</u> necessarily mean that survivors want medical tests and interventions to end. Especially since many research papers which argue against repeated investigations for sexually abused people suggest only psychological treatments, instead. Rather, survivors want any medical investigations to be appropriate and informed, respecting and understanding their own history of abuse (*see Advocacy Issues, Chapter 9).*

3) Misdiagnosis and inappropriate treatment:

'Iatrogenic' health problems can also happen when conditions are mis-diagnosed. Then inappropriate medications may be prescribed, and this may be damaging over the medium to longer term. Examples of this problem can include non-epileptic seizures, when treated with epilepsy medications; and paradoxical vocal cord dysfunction (PVCD), when treated with asthma medications.

In Advocacy Issues (see chapter 9), we discuss the dialogue with medical professionals, which sexual abuse support organisations like Wellbeing Scotland and KASP would like to see. This is especially the case in relation to polypharmacy, the treatment of chronic pain, and the need for 'trauma-informed' diagnosis and treatment.

Chapter 8: Sensitive Practice by Health Professionals

What research and survivors recommend

"The best ones make you feel at ease … they come out with comforting words, they're patient … you can talk about anything, you don't feel embarrassed. They are down to earth, no airs and graces!"

"It's about talking to people in a way that you want to be talked to yourself."

In *Surviving Well,* the booklet we produced for health professionals, sexual abuse survivors from Open Secret of Wellbeing Scotland and KASP talked in depth about both positive and negative responses they'd had from professionals. In particular, they talked about the environment and attitudes they met at the health centre, the hospital, clinic or dentist, and about responses when they first revealed a history of sexual abuse.

There were some negative responses which you can read about in more detail in that booklet, like dismissing it by saying they hadn't time to talk about that, or telling them to forget the past and just move on. One survivor made this very powerful comment about such attitudes:

"When you're told to keep quiet, medical professionals are saying the same thing as abusers do."

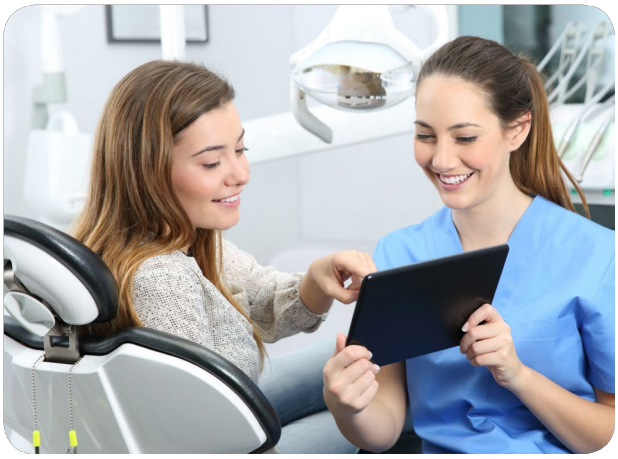
Some staff assumed that an abuse history meant that all the survivor's health problems must somehow be psychosomatic, while occasionally, staff reacted in a callous way. A male survivor recalled: *"It's taken you courage to say it … then I was told, 'what do you want me to do about it?' 'How old are you?' - more or less 'Man up and deal with it'."*

Fortunately, there were many positive responses, which you can also read about in more detail in *Surviving Well.* Survivors of sexual abuse were keen to help support good practice and make it more widespread through publicity. We want these to become the kinds of responses you can expect as patients and clients, and something you could promote, in collaboration with health professionals (*see "designing training materials" in chapter 9).*

These were the main points survivors praised (or suggested themselves) about creating safe health settings:

- The need for kind, considerate, accepting and sensitive receptionists, who respect confidentiality. Not receptionists with a judgmental attitude who are insensitive to confidentiality, e.g. demanding to know why they want to see the doctor for emergency appointments.

- Having a chaperone available:



"Make certain there's always a chaperone available in dental surgery or health centre. This also protects the doctor or dentist from ever being accused of something they haven't done."

- A choice of gender of health professional where possible:

"I didn't see a dentist for years and years and years. Then I started seeing one, what a difference - it was a woman, which helped - I just couldn't cope with a man's face close up, his breath on me …… I said straight out to this (new) dentist, I had a problem of abuse and I would prefer a woman. She said, 'oh that's fine'"…

- Sensitivity in examinations, especially with oral, facial and reproductive care, a "stop" signal available during examinations, and a running commentary to explain what is happening.

"It's telling you and keeping on explaining, because when you don't know, your imagination just runs doesn't it?"

- Permission always asked for students to be present:

"Yes, because if they only ask you when the student's already there, you don't like to be rude and tell them to go away- that can be difficult"…

Disclosing a sexual abuse history: What was helpful to the survivors?

- Expressing genuine sympathy and sadness when people reveal abuse:

"And my GP said at once, 'I'm sorry, I'm so sorry that happened to you'. He said it as a human being"

- Being believed and listened to:

"What means a lot is a good listener who reduces my anxiety – then I can be myself, and get my point across. Being believed is really important … the sense of that which comes across to me."

- Gently persisting in asking the question if they have strong grounds to suspect sexual abuse may underlie a health problem. This can help to protect children and teenagers, too as this man suggests:

"I had decades of never being asked by health professionals or psychiatrists or psychologists. Yet I had so many different things wrong with my body, and I had panic attacks, really frightening flashbacks … things that didn't even make sense to me then. … It's so important if health professionals are aware, and think about the possibility of abuse if children are showing mental health issues, blackouts, odd behaviour … I was chain smoking by age 12 … also if kids are bunking off school; I did that a lot."

- Perceiving that someone is at crisis point, who needs support now, and giving them a bit of extra time to genuinely listen. This doesn't mean great amounts of time: an extra ten minutes or a double appointment could make all the difference:

"One day when I was feeling really depressed and suicidal - I admitted it (abuse history) to a GP in the surgery - he sat and spoke to me for ages. I didn't know him previously, he was just a locum - I didn't have anyone (else) to speak to at that time."

- Referring them on for more help IF the survivor wishes it, without simply fobbing them off elsewhere. Knowing about local support agencies and counsellors:

"And my doctor said, that time when I was in a really bad way - 'I want you to contact Open Secret. Here's the number'. And he already had the number in his head! I'll never forget that he didn't have to look it up."

- Offering support to take the first step, such as making the first call to a support agency:

"*The ones who ask – 'do you have someone to go with you – would you like someone to go with you the first time', or who make the 'phone call … because you could be scared to do it yourself."*

- Noting abuse history in medical records – but only in a sensitive way. Most survivors in our projects said they would like the fact of their abuse history to be included in their medical records. This would explain some posttraumatic symptoms and reduce the need to repeat their history over and over to professionals. But there were many anxieties about the confidentiality of this information. There was support for agreeing with professionals a short straightforward paragraph for their records - not detailed, humiliating information about their abuse.

Helpful responses for diagnosis and treatment: what survivors appreciated

- Exploring open-mindedly for a diagnosis like any other patient, without prejudice or preconceptions; not automatically assuming it is psychogenic.

"What do we want? To be listened to and not to be judged."

- Being able to have an informed discussion about whether particular problems might indeed be linked to their abuse, e.g. gynaecological or urinary problems.

"I want to be able to ask in a matter of fact way 'look, could my serious bladder problems be related to the abuse I had?' And get an informed answer, and a matter of fact answer".

- Staff who are knowledgeable about the effects of sexual violence, or keen to learn *more:*

"I think she (GP) at first felt,' this is outside my league', but she learned more about it and didn't say, 'go away and talk to someone else instead of me.'"

- When health professionals themselves took the initiative to see patients who are survivors a bit more often, survivors found their anxieties dropped, their need to see professionals decreased, and relationships improved:

"There is this attitude you keep meeting when you get one appointment somewhere. 'That's OK we don't need to see you again'. Or 'go to the gym and get yourself fit!' But the pain management team's attitude was, 'you know where I am…' I know I can go to the pain clinic whenever I want, and this relaxes me".

- Professionals who give them some control over their recovery, and who understand that people may recover, then become worse, then recover again. Survivors really value health staff who understand and stick with them.

These are all points which you as survivors, or as groups of survivors, may want to impress on your own local healthcare services, with the backing of your support agencies. They are not 'rocket science' - but can make a great difference to the sense of welcome and safety that people find in a healthcare setting.

Principles of Sensitive Practice

It's really interesting to see how far CSA survivors in our physical health projects came up spontaneously with so many similar points to the Handbook on Sensitive Practice for Health Care Practitioners: Lessons from Adult Survivors of Childhood Sexual Abuse, and also to other published good-practice guides. *(There are examples of these in the Resources and Websites section of this booklet, Appendix 2.)*

In the handbook by Candice Schachter and colleagues are some important principles, which we summarise below.

1) Respect

"*To the person who has been abused, it certainly means a great deal."*

2) Taking time

"It's the health care practitioners that … stop and give you a moment, and that's one of the biggest healing things right there, that moment."

3) Rapport

"Showing some empathy, some caring, some concern … making me feel that I'm a person as opposed to another client file going through."

4) Sharing Information

"[He always gave] a reason why he was doing something, which was great … It wasn't just doing things and then leaving you in the dark. If the person took ten seconds to tell me, 'This is why I'm going to do it,' it would stop the mind from running."

5) Sharing control

"Sexual abuse involves losing control over one's body. Sharing control of what happens enables people to be active participants in their own care, not passive recipients of treatment. In this way, the clinician works with, rather than on, the client, e.g. 'If you are not comfortable with doing it that way, maybe we can make adjustments'"…

6) Respecting boundaries

"As a survivor, I need to know that that person is not going to invade my space. Or do harm to me. Not necessarily physically, but emotionally."

(Although it is a part of 'respect' (point 1), it is also a principle in its own right, because respect for boundaries is so important to a sense of safety for survivors of CSA.)

7) Fostering mutual learning

Most survivors are interested in helping health staff to learn about the health effects of CSA.

8) Understanding non-linear healing

Healing and recovery from childhood sexual abuse do not simply move forward in a straight line. Much more often people make progress, become ill and retreat a bit, then make progress again.

9) Demonstrating awareness and knowledge of interpersonal violence

This doesn't mean people have to be experts: just that they have taken the trouble to read and learn a bit about the issue and want to learn more.

"She had a book and a pamphlet on a table nearby where I was sitting that talked about sexual abuse, and so immediately that said to me … she is open to this and therefore if it comes up I know that I'm in good hands…"

(Summarised with permission from: Schachter CI., Stalker CA., Teram E., Iasiuk GC., Danilkewich A . 2009. Handbook on Sensitive Practice for Health Care Practitioners: lessons from Adult Survivors of Childhood Sexual Abuse, Ottawa: Public Health Agency of Canada). https://www.integration.samhsa.gov/clinical-practice/handbook-sensitivve-practices4healthcare.pdf

Chapter 9: Some Advocacy Issues Arising from This Pack

For Survivors and Their Support Organisations

Everyone will have their own ideas, after reading this information booklet, about what needs to be done to create the best possible healthcare for survivors of childhood sexual abuse. This chapter simply offers some suggestions to consider – based on our findings - about issues which survivors and their support agencies might wish to take up.

There are ten themes below which could be raised with health services, social services, in the media, or with representatives such as MSPs and councillors. We hope many of these can involve collaboration with interested, concerned health professionals. It will be an exciting journey to bring about change, and to see it happening in Scotland.

1) Training Issues

- **Funded, confidence-building training for all health professionals is needed, to address fears and anxieties which many have about CSA, including how to work positively with disclosure.**

So many survivors wish they had been asked about a history of sexual abuse, yet professionals avoided the question- sometimes for many years. This reflects the fact that many health professionals feel anxious about CSA. They may believe it's very complex and that they are not trained enough. They may fear they will have to start a child protection investigation or get caught up in a family conflict. They may fear that asking will make patients upset, offended or more ill. Some health professionals who are survivors themselves will not feel ready to address their own issues.

Fears about patients' reactions are rarely justified in practice; some routinely explore for a history of CSA already or are meant to do so, under provisions for Routine Inquiry (see below). But the anxieties are genuine, so they need to be acknowledged. All medical staff need the opportunity to work through them. We also believe that training, to be effective, needs to be supportive and reflective, allowing people fully to voice their anxieties and feel safe about expressing their own experience. It will not work if it is stern and instructional.

Scotland-wide trauma training

Positive moves were made when in 2017, NHS Education for Scotland published a national training framework in relation to working with a range of forms of trauma, *Transforming Psychological Trauma: a knowledge and skills framework for the Scottish workforce*. They aim to continue rolling it out to a very wide section of staff who work with, or are likely to work with people with trauma, to enable them both to react positively to disclosure, and to understand and respond to people's needs more sensitively. (http://www.nes.scot.nhs.uk/education-and-training/by-

discipline/psychology/multiprofessional-psychology/national-trauma-training-framework.aspx)

While we have difficulty with its four-tiered level of trauma training (because a survivor may choose to confide in a staff member of any status or level, at any time) and while we believe that within this, *sexual abuse* trauma training requires a specific input, we hope the information and the direct survivor feedback in *Surviving Well* and *Surviving Better* will prove helpful to people undertaking this training framework.

In trauma training and in professional development courses on working with survivors of sexual abuse, and in Routine Inquiry (see below) there needs to be really open discussion of prejudices and assumptions made about survivors once their history is known.

It will not be helpful to encourage survivors to tell and staff to ask, if the kinds of automatic assumptions survivors often experience - that physical health problems are invariably psychogenic, and survivors weak, difficult or hypochondriacal - then follow. Just as important as asking the question is to ensure that knowledge gained and recorded about an abuse history leads to informed judgment and open-minded attitudes towards you as a survivor.

- Training also needs to ensure that staff understand survivors' own fears and anxieties in healthcare settings and put into practice positive ways to create safe and reassuring health settings.

Excellent perinatal advice from Healthcare Improvement Scotland

Guidance from the maternity improvement forum of Healthcare Improvement Scotland has some sensitive and informed guidance for midwives and obstetricians working with women survivors of sexual abuse. It would be worth pursuing to check if guidance issued in 2011 is routinely being followed, and also to press for similarly sensitive guidance from all services.

We believe this is a genuinely client-centred and survivor-centred approach. Notably it stresses listening and belief and asks staff to find out what women want from them - not the other way round. It calls for individualised care. It understands safety, and why records should only be on a 'need to know' basis. It knows trauma work can distress staff too. Among its recommendations are:

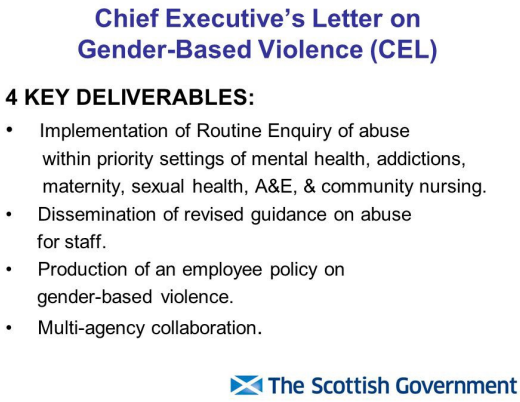
- The reality of sexual abuse affects women from all walks of life.
- Be aware of clinical symptoms and indicative behaviours which could potentially occur ... e.g. non-engagement with maternity services, unease with touch or examination.
- Listen, believe and accept.
- Respond with individualised care planning, including assessment of current safety (for both mother and baby).
- Find out what the woman needs from you.
- Be sensitive to potential triggers e.g. the language you use, or some smells such as aftershave may provoke memories.

- With the woman's consent, maintain accurate records that are easily accessible on a 'need to know' basis. Be aware, however, of duty of care requirements where there are child protection issues.
- Know about local and national support agencies.
- Know how to seek support for yourself.
- Give clear explanations, and obtain informed and ongoing consent prior to and during all care provision, especially relating to physical contact.
- Do truly endeavour to maintain privacy and dignity at all times, e.g .aim to have the minimum number of attendants, and aim to have minimal interventions.

For further details see:

http://www.healthcareimprovementscotland.org/our_work/reproductive,_maternal_child/programme_resources/victims_of__sexual_abuse.aspx

2) Monitoring the progress of "Routine Inquiry"



Training should prepare services for their obligations under **Routine Inquiry**. Survivors will want to check if healthcare professionals are meeting the responsibilities now placed on them to ask about an abuse history, which often has serious consequences for patients' health. The Scottish government's **National Gender-based Violence and Health Programme** has since 2008 been rolling out a detailed agenda to tackle gender-based violence through health services; and this includes routine inquiry, in some health settings, about various abuses which largely (but not solely) affect women and girls.

While the programme's support materials and training clearly stress the value of inquiring sensitively about possible CSA history, initial responsibilities for routine inquiry have been linked to domestic abuse (which of course can include sexual violence) rather than to childhood sexual abuse. However, this strategy continues to expand and develop. This is important since the strategy continues to expand and develop. Indeed it's vital that it does - because survivors of CSA, both female and male, are to be found in a very wide range of health services.

For example, two of the six priority services making routine enquiry of domestic abuse (of women) are also required to carry out routine enquiry of CSA with both new female and male patients presenting to their services. These are mental health and substance misuse services. Both have a disproportionate number of survivors presenting to them.

Information about current training and support for healthcare staff working with abuse issues can be found at http://www.healthscotland.scot/health-topics/gender-based-violence/gender-based-violence-overview/routine-enquiry-of-abuse

3) Sensitively improving history-taking about abuse

Giving actual details about assaults you suffered as a child, and areas of the

body repeatedly affected, often proves difficult or distressing. But if you feel that information would be important in helping your diagnosis or treatment, perhaps survivors, their agencies, medical professionals and researchers could get together to develop a sensitive questionnaire. People could fill this in, online or in hard copy, avoiding the need to talk one-to-one about very difficult things.

They might also wish to call for more trained, specialist nurses to work with certain consultants: e.g. in ear nose and throat, gynae. and gastro-enterology departments. Survivors would then have the option of discussing any details of their sexual abuse history with these nurses.

4) Developing useful information materials

Survivors and their support agencies might be interested in producing for health centres, clinics, dental surgeries etc:

- **POSTERS** for display on 'Do's and Don'ts' in working with the disclosure of CSA; and
  'Do's and Don'ts' in providing safe healthcare settings;

- **LISTS** of local services and helplines and websites, for young people and adults who have suffered sexual assault.

5) More joint work with health professionals, in producing "trauma - informed" health services

While we welcome the national development of training in trauma- informed services in Scotland, it's important that third sector agencies experienced in working with survivors themselves, and their own service users, are consulted and involved in the development of such training.

Wellbeing Scotland and KASP have called for trauma-informed services to be sure to include:

- Building in ways to avoid the risk of re-traumatising people;

- Understanding the ways in which trauma may be encoded into the brain, which would prevent the unhelpful advice of 'forget about the past and think about the future';

- Understanding the effects of dissociation, where many survivors learned as children to 'escape' from abuse and violence by 'spacing out'. But this can mean some patients may miss appointments or medication, appearing uncaring when in fact they simply don't remember the information.

- More multi-disciplinary groups of professionals with a special interest in the longer-term health effects of child abuse are needed who could meet regularly and work

collaboratively. These multi-disciplinary groups could include, e.g. interested GPs and dentists, and specialists in psychosomatic medicine, paediatric medicine, gynaecology, forensic, GI, urinary, respiratory and chronic pain conditions, along with third sector agencies.

Wellbeing Scotland and KASP hope the positive development in promoting trauma informed services will lead to closer cooperation and joint planning, for they have long called for more opportunities for joint learning with medical professionals. They also want to increase imaginative joint projects. Some examples have already been of great benefit to health professionals, the voluntary sector and survivors. You may know of others in your own area. For instance

- Wellbeing Scotland previously had a partnership project with NHS Forth Valley offering Eye Movement Desensitization and Reprocessing (EMDR) and Emotional Freedom Techniques (EFT) to survivors of childhood trauma.

- KASP: "Building more local groups of specialists and support agencies are part of the future - such as working with Fife Psychological Department who initiated training in the Solihull Approach. This approach initially worked with parents and children from universal to complex needs 0-18 years, although it was soon realised that it was relevant and beneficial to adult survivors. It is based on the Solihull Approach model of containment, reciprocity, and behaviour management and understanding trauma."

6) Using the Government's own Quality Strategy to Call for improvement of care

Much of the good practice by health professionals towards survivors of sexual abuse matches closely with the approach of **person-centred care**, which NHS Scotland actively wishes them to pursue. Much of the poor practice survivors have met at times contradicts those principles. You can find out more about this strategy, and call for it to be put into effect when you are dissatisfied with current care or attitudes towards survivors of abuse, through looking up:
https://www2.gov.scot/resource/doc/311667/0098354.pdf

The Quality Strategy emphasises safety and freedom from harm, person-centred practice which shows clear communication and compassion, and effective treatments and support. Person- centred care promotes independence and autonomy rather than control. It sees patients as equal partners in planning, developing and assessing care to make sure it's appropriate for their needs. It involves putting patients and their families at the heart of all decisions. Survivors and their support agencies can make use of all these principles to improve both attitudes towards their care and support, and the support itself.

7) Promoting Patients' Rights

It's important not only to promote excellent practice but to ensure that survivors have a means of redress, if their care falls short.

Both health professionals and service users who are survivors of sexual abuse need to feel confident about the fairness and equity of health settings towards vulnerable

clients. That includes the right to make a reasonable complaint, without being penalised or even excluded from services.

Some worrying issues arose from groupwork and interviews with survivors from Open Secret of Welbeing Scotland and KASP. When survivors had tried to make a complaint, some had been labelled “difficult”, or even barred from a GP practice.

“You get a label of being ‘difficult’ if you speak up for yourself”…

Also, because some survivors suffer from anxiety or even fear in healthcare settings, this can unintentionally come out, especially from male survivors, as aggressive demands. It is useful to be able to explain this.

Positive experiences were related in our groupwork projects too. Survivors were extremely appreciative of doctors, nurses and other health professionals who weren’t afraid to stand up for their patients/clients with other professionals. For instance, they would keep writing or ‘phoning to access a service that was not being responsive, or to pick up on insensitive treatment:

“My GP was furious about my treatment by one psychiatrist and made a complaint. Got an apology from the psychiatrist that she had made me upset.”

Wellbeing Scotland and KASP believe it is important to have regular discussions with health professionals’ organisations so that service users feel reassured and aware about what their rights and responsibilities are, and what are their needs might be for advocacy in health settings. We also ask health professionals to understand survivors’ fears and frustrations after many years of ill health. Indeed, more understanding of the difficulties is needed on both sides.

Advice from the Royal College:

The Royal College of GPs in Scotland has asked us to make everyone aware that the **Patient Rights (Scotland) Act 2011** may help them address some of the issues above. The Patient Rights (Scotland) Act 2011 (see https://www2.gov.scot/Topics/Health/Policy/Patients-Rights

gives all patients the right that the health care they receive will: consider their needs; consider what would most benefit their health and wellbeing; encourage them to take part in decisions about their health and wellbeing, and provide them with the information and support to do so.

It also gives patients a right to give feedback and comments, and to raise concerns or complaints about the care they’ve received. It requires that health boards encourage, monitor and learn from this feedback There is a Charter of Patient Rights and Responsibilities, and the Act also gives access to the independent Patient Advice and Support Service. (http://www.cas.org.uk/pass) PASS can help you give feedback about your healthcare, and direct you to advocacy or communication support services.

In the ‘Resources and Websites’ Appendix of this booklet there is a section on contact details for organisations in Scotland which can further assist on patients’ rights issues, but which may also be able to take forward advocacy and campaigning issues, on

behalf of survivors and their support organisations, which we have discussed in this chapter.

8) A wider range of treatments and therapies, & their consideration in Evidence-Based Practice

Survivor agencies are keen for more, and more regular, dialogue with medical professionals on closer scrutiny of polypharmacy, and possible alternatives to it. We want to collaborate with medical and psychological services to consider what benefits were experienced and recorded by survivors who undertook therapies such as Indian Head Massage, Reiki or EFT (Emotional Freedom Technique) during groupwork projects and individual support work.

Because of the drive for 'evidence-based' medicine nowadays, papers in peer-reviewed journals which assess treatments and therapies are important and are given priority. We need more evaluations in peer-reviewed journals of a wider range of therapies and treatments, including complementary therapies. These evaluations need to involve survivors and other service users themselves, and to include the use of 'soft' outcomes which are important to the recovery of service users.

The determined, informed and continuing campaign by Sandra Whyte and her colleagues (Whyte et al.2012) gives one example, in this case of using the Scottish Parliament's public petitions mechanism to press for change and improvements in therapies available.

9) Free or low-cost access to complementary therapies

Many survivors in our projects were frustrated that they could not access some treatments and therapies on the NHS, or that there was only short-term funding for them, or that they were too expensive. Indeed, the Open Secret service itself was only able to run the programmes described when these were funded. Cost was a particular problem for people who were too unwell to work. Survivors who had found complementary therapies had improved their health and wellbeing remarked, e.g.:

"I want to be able to access acupuncture, massage and so on on the NHS. I've asked but this hasn't been possible. I had some complementary therapies with KASP and they were helpful, but I haven't been able to get anything like that on the NHS".

"A chiropractor, in contrast (to NHS services) helped with my pain… but I had to pay for one myself".

10) New research possiblities

Here are a few examples which might prove useful.

- Long-term studies could be done (with their permission of course) of the physical health of young people whose sexual abuse history is known and recorded.
- Research could take place with specialists who work against a range of sexual and other violence such as domestic abuse or political torture, to find effective evidence-based treatments and pain services.
- The techniques used by sports medicine in its detailed examination of stress injuries and repetitive injuries could be studied, with a view to adapting these for abuse-related injury, and hopefully to lessen pain and suffering in CSA survivors.
- Sensitive research with CSA survivors themselves and their support agencies could take place, offering a high degree of confidentiality, on the types of childhood assault they experienced, and any possible links with their present health problems.

Chapter 10: Our Complementary Therapies Experience and Evaluation

Please note! This chapter is for information and discussion only. We are neither advocating a particular therapy, nor suggesting that one is superior to another. We are not qualified to make such recommendations, and in any case, comparisons among the therapies would need larger-scale, longer-term research projects, with clearly-agreed 'outcome indicators'.

However, there is considerable interest among CSA survivors in complementary therapies, especially in safe bodywork and in its ability to reconnect survivors with their own bodies in supportive ways. So, you may find it helpful to see how survivors experienced our own projects.

This briefly describes feedback which the Open Secret service received from survivors about complementary therapies it was able to provide. First, as part of the Complementary Therapy service for survivors of CSA, funded by Long term Conditions Alliance Scotland. (Now the Alliance). The service was operated by Open Secret of Wellbeing Scotland in partnership with two other agencies supporting survivors, KASP and the Moira Anderson Foundation. They recruited sessional therapists, offering a range of therapies including acupuncture, Reiki, yoga, meditation and relaxation, Indian Head Massage, reflexology and Thai hand and foot massage.

Members of our Physical Health Groupwork Project could choose these therapies while the Complementary Therapies Project was running. After this, the Groupwork Project itself included taster sessions of therapies, which also included EMDR, EFT and Mindfulness, offered in collaboration with NHS Forth Valley.

Aims of the Complementary Therapies Project were:

- To enable survivors to learn techniques for self-management of long-term health conditions (Many were also taught self-relaxation techniques, and some self-administration of Reiki 1);
- To empower them to take more control of their recovery;
- To reduce dependence on medication;
- To enable them to be more assertive about their own healthcare needs.

Reiki, Indian Head Massage and reflexology were the most often requested. This is likely to be because of the less intrusive nature of these therapies for survivors of CSA, which allow clients to remain fully clothed.

Complementary therapies were highly evaluated and valued by the survivors who took part. For the survivors, the most valued aspects of complementary therapies were:

Feeling cherished, nurtured and cared for, sometimes for the first time; the calm, restful, gentle atmosphere; relaxation and lowered anxiety; the professionalism and skill of, and their trust and confidence in, the therapists; their satisfaction in the self-management techniques learned; ability to manage pain better with fewer painkillers or sleeping

tablets; the ability to tolerate being touched in safe supportive ways; and general sleep improvement and greater energy.

However, while the therapies gave many clients and ability to manage pain better, few people reported actual lessening of their physical pain.

The groupwork projects reported:

Large reductions in daily anxiety; increased ability to sleep more soundly, or to return to sleep quickly. Those who learned Reiki techniques reported considerable growth in confidence. One client for instance, who took part in a CD recording about her experiences, had barely left her home for the previous two years, yet was confident enough to go shopping and make her own way to the group.

It is an important point that the improvements in mental health which happened often enabled improvements in physical health too – such as feeling able to go out and take exercise instead of being afraid to leave the house, or finally being able to achieve good and consistent sleep.

There was an important warning from the evaluation for funders, commissioners of services and others who see self-management, self-education packages and e-learning as the way forward - often as a way to cut health costs and staffing. While self-management was found helpful, survivors became able to use and benefit from it **through the personal caring and growth of trust and self-confidence which they gained from the empathy and skills of the complementary therapists.** This suggests that there cannot be simple ‘short-cuts’ to better self-management of long-term health conditions through making people use educational packages by themselves. Especially if they are people with issues of trust, anxiety and self-doubt.

The evaluation judged that the most important preliminary work was:

a) An initial interview, to explain the approach and anticipate survivors’ worries.

b) A choice of therapies, with awareness of survivors’ concerns about touch.

c) The opportunity to take up home visits by the therapists, for people who otherwise would not physically or psychologically be able to attend.

d) Discreet checks on their well-being, if they failed to attend.

e) The understanding that kindness, compassion and individual caring were integral to therapy - not just a ‘placebo’ effect.

The evaluation recommended that research collaboration with a university be pursued and that funding for this would be very worthwhile. It would be valuable to include the results of any trial into peer-reviewed journals, given the dominance of ‘evidence based’ medicine, its reliance on peer-reviewed research to judge effectiveness, and the current scarcity of such research.

Appendix 1: References and Other Useful Reading

Incidence and Prevalence of Childhood Sexual Abuse

Statistics vary - sometimes considerably - according to definitions of CSA used, samples used, the research methodology employed and several other factors. Under-reporting is a considerable issue in a subject surrounded by shame and secrecy. There's a considerable mismatch between high numbers of adults who report a CSA history, and officially-known cases of CSA. Chapter 1 in *Tackling Child Sexual Abuse* (see below) discusses these issues in detail, while here are some other papers which discuss the complex issues involved, and which consider results from a range of studies.

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Appendix 2: Resources and Websites, including Minority Ethnic Health Contacts

Improving Healthcare Settings, Understanding & Reducing Problems & Fears:

Bass E. and Davis I. (2008) *The Courage to Heal: A guide for Women Survivors of Child Sexual Abuse,* 20th Anniversary Edition, New York: William Morrow.

Lella Baker (2009), Tips for partners, friends & family of survivors,, Pandora's Project, https://cdn.atixa.org/website-media/atixa.org/wp-content/uploads/2015/12/12193455/Tips-for-Partners-Friends-Family-of-Survivors.pdf

Canadian Women's Health Network, *Getting Through Medical Examinations - A Resource for Women Survivors of Abuse and Their Health Care Providers*, http://www.cwhn.ca/en/node/42905

Some dental fear websites:

http://www.dentalfearcentral.org/fears/abuse-survivors/

Dental Fear Central: 'Sexual Abuse in Childhood and Dental Fear - An Interview with Clinical Psychologist Dr Carmen Santos', http://www.dentalfearcentral.org/fears/abusesurvivors/interview/

http://www.dentalfear.com/santos.asp

Larijani, H. and Guggisberg, M. (2015)'Improving Clinical Practice: What Dentists Need to Know about the Association between Dental Fear and a History of Sexual Violence Victimisation' https://www.hindawi.com/journals/ijd/2015/452814/

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Havig K. (2008) 'The Health Care Experiences of Adult Survivors of Child Sexual Abuse: A Systematic Review of Evidence on Sensitive Practice', *Trauma, Violence, Abuse*, 9 (1): 19-33.

Living Well: Sexual intimacy after sexual abuse. Information for Partners. https://www.livingwell.org.au/relationships/partners-sexual-intimacy/

MENding UK (2014) *Helpful Tips for Survivors of Childhood Sexual Abuse (particularly in medical situations),* http://www.mending-uk.org/wp-content/uploads/2015/07/Helpful-advice-for-survivors.pdf

Mcgregor K., Glover M. Gautam J. and Jülich S. (2009) 'Working sensitively with child sexual abuse survivors: what female child sexual abuse survivors want from health professionals', *Women Health*, 50(8):737-55.

Malone, C., Farthing, I. and Marce, I. (1996) *The Memory Bird: Survivors of Sexual Abuse,* London: Virago.

Maltz W. (1991*) Sexual Healing Journey: Guide for Survivors of Sexual Abuse.* NY: HarperCollins.

Montgomery E. Pope C. and Rogers J. (2015) 'The re-enactment of childhood sexual abuse in maternity care: a qualitative study', *BMC Pregnancy and Childbirth*, 15, 194.

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Nelson S. (ed) (2020) *Surviving Well? Good practice for health professionals working with survivors of childhood sexual abuse*, 2020 Edition, Wellbeing Scotland (formerly Open Secret), Alloa.

NES Scotland (2017) *Transforming Psychological Trauma: a knowledge and skills framework for the Scottish workforce* (http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/multiprofessional-psychology/national-trauma-training-framework.aspx)

Our Bodies, Ourselves (2008) *How Sexual Abuse Can Affect Pregnancy and Birth.* https://www.ourbodiesourselves.org/publications/pregnancy-and-birth/

Positive Birth Movement (2016) *Speaking frankly about the impact of sexual abuse on the birth experience.* https://www.positivebirthmovement.org/giving-birth-as-a-survivor-of-abuse/
Sperlich M. and Seng J. (2008). *Survivor moms: Women's stories of birthing, mothering and healing after sexual abuse*. Eugene, Oregon: Motherbaby Press.

Schachter C., Stalker C. and Teram E. (2009*) Handbook on Sensitive Practice for Healthcare Practitioners: lessons from Adult Survivors of Childhood Sexual Abuse,* Public Health Agency of Canada, National Clearinghouse on Family Violence.

Teram E., Stalker C., Hovey A., Schachter C. and Iasiuk g.(2006) 'Towards malecentric communication: sensitizing health professionals to the realities of male childhood sexual abuse survivors', *Issues in Mental Health Nursing,* 27 (5): 499-517.

Tips to Help Sexually Abused Victims Overcome Their Fear of Pap Smears (2012), https://www.medicaldaily.com/tips-help-sexually-abused-victims-overcome-their-fear-pap-smears-242868

Patients' Rights, Advocacy and Campaigns (general issues, including trauma issues)

The Scottish Health Council, http://www.scottishhealthcouncil.org/home.aspx;

The Patients' Association: http://www.patients-association.org.uk
www.Scotlandpatients.com

The Scottish Independent Advocacy Alliance: https://www.siaa.org.uk/

The Scottish Public services ombudsman, http://www.spso.org.uk/

Scottish Association for Mental Health (rights issues): https://www.samh.org.uk/about-mental-health/know-your-rights

CAPS Independent advocacy (mental health): http://capsadvocacy.org/links/

The Royal College of GPs in Scotland has asked us to make professionals, survivors and their support agencies aware that the **Patient Rights (Scotland) Act 2011** may help them address some of the issues that concern survivors abut their treatment in healthcare settings. above. This Act (see http://www.gov.scot/topics/Health/Policy/Patients-Rights)

gives all patients the right that the health care they receive will: consider their needs; consider what would most benefit their health and wellbeing; encourage them to take part in decisions about their health and wellbeing, and provide them with the information and support to do so.

It also gives patients a right to give feedback and comments, and to raise concerns or complaints about the care they've received. It requires that health boards encourage, monitor and learn from this feedback. There is a Charter of Patient Rights and Responsibilities, and a series of "your health, your rights" factsheets, available at:

https://www2.gov.scot/Topics/Health/Policy/Patients-Rights/Patients-Rights-Access

the Act also provides access to the independent Patient Advice and Support Service. PASS can help patients to give feedback about their healthcare, and direct them to advocacy or communication support services.

https://careinfoscotland.scot/topics/your-rights/patient-advice-and-support-service-pass/

Some contacts for black and minority ethnic (BME) health support and advice in Scotland

Please note that most are not usually specifically for sexual violence issues, but they offer culturally sensitive, knowledgeable and confidential services where such issues and others can be discussed.

Community health: REACH Community Health Project is a national third sector organisation with a key strategic role in improving the health, wellbeing and health care provision of Black and Minority Ethnic (BME) communities in Scotland. http:// www.reachhealth.org.uk/ REACH has units engaged in culturally sensitive Service Provision, Policy and Research as well as Training and Development.

Minority Ethnic Health Inclusion Service: This service is part of NHS Lothian. It aims to improve the quality of and access to Primary Health Care services by the black/ minority ethnic and refugee communities across Lothian. https://www.evocredbook.org.uk/organisations/minority-ethnic-health-inclusion-services-mehis/001b00000065v4uAAA

Health issues, including sexual violence, for refugees and asylum seekers:
https://www.scottishrefugeecouncil.org.uk/direct-support/

The Ethnic Survivors Forum: this offers culturally sensitive support services for minority ethnic adult survivors of childhood sexual abuse resident in Scotland (16+). It includes confidential, free, multi-lingual telephone helpline. The website offers information and resources. They offer a culturally sensitive befriending service and face to face confidential, free counselling and support.
https://edspace.org.uk/provider/ethnic-survivors-forum/

Trauma Counselling Line Scotland: Confidential telephone counselling service for adult survivors of childhood abuse including survivors from BME communities https://www.health-in-mind.org.uk/services/trauma_counselling_line_scotland/d15/

"Honour" violence: 'For Honour & love', a DVD, aimed at people aged 16 and over which deals with topics such as violence against women and honour killings. Age 16+ Also available in Arabic and Kurdish.
http://vipshop.bothybiz.com/store/products/category/dvds/

About Wellbeing Scotland

(formerly Open Secret, a name retained by our Trauma Services)

Wellbeing Scotland is a Scottish charity (SC 024065), established in 1994 that operates across Scotland. We have office bases in Alloa, Stirling, Edinburgh, Glasgow and Larbert. We offer:

- A free confidential service to survivors of childhood abuse and people who have had an impact on their wellbeing through adverse life circumstances.
- support to partners and friends
- support to other workers and organisations working with abuse and wellbeing issues
- support for non-abusing parents of children who have been abused or who have experienced adverse life circumstances.

We have specialist services for children and young people, people in prison and people abused in care.

Counselling/ Support

Offering a safe place to talk about things that may be affecting your life. It is your choice what you discuss, and we will go at your pace. You will have a first appointment to decide which service would suit you best and then you will be offered as many sessions as you need. We have counsellors based across Scotland and will try to ensure that you are seen locally.

Advocacy

If you need support with practical issues such as benefits, housing, criminal injuries compensation claims etc. we have workers who can help you. We can also help you to access records of your time in care.

Befriending

You will be linked with a befriender who will help you gain confidence in dealing with new experiences. A befriender can help to establish links within the local community and to access social, educational and recreational opportunities.

Groupwork

Many people find it helps to share their experience with others to support one another. We offer women's support groups, men's support groups (Man Cave in partnership with the WASPS, Alloa Football Club), art therapy, self-management, trauma informed yoga. drama and writers' groups.

Library and Resources

We have a large library in our offices with over 500 books on childhood abuse, health related issues, self-help books etc.

Training

We deliver training on Basic Awareness of Childhood Abuse, Working with Trauma, Vicarious Trauma and Self Care, Mental Wellbeing, Dissociation, Self-Awareness, Domestic Abuse and Coercive Control, Suicide and Self-harm and a number of other bespoke training programmes requested by organisations.

Getting Involved

A very important part of our service is that we will learn how to improve by the people who use our services. We support a number of campaigning and service user input groups and events.

Website www.wellbeingscotland.org

Facebook https://www.facebook.com/Wellbeingscotland/
https://www.facebook.com/opensecretorg/

Twitter https://twitter.com/Wellbeingscot
https://twitter.com/opensecret5

Wellbeing Scotland
14 Bank Street
Alloa
FK10 1HP

Tel: 01324 630 100

About Kingdom Abuse Survivors Project (KASP)

Kingdom Abuse Survivors' Project (Scottish Charity No. SC023079) provide a diverse range of support services to enable adult survivors of childhood sexual abuse throughout Fife to eliminate the debilitating effects that the abuse has on their lives.

Counselling and support to anyone over the age of sixteen who has been sexually abused as a child, to partners, family members or anyone supporting someone who has been abused. This is available in the Kirkcaldy and Cupar premises and an outreach service is provided to ensure equity of access for all survivors across Fife.

Electronic Counselling and Support can be arranged for those who prefer this medium.

Group activities - therapeutic and social support groups are provided according to demand.

Information Resource - a wide range of publications is available.

Training - We provide training on understanding and working with adult survivors of CSA to voluntary and statutory agencies throughout Fife and beyond. The training we provide typically covers the impact of early trauma and abuse, recognising trauma symptoms and how to sensitively and effectively respond to disclosures of abuse. We are also able to provide bespoke training geared specifically to the particular needs of an agency.

Domestic Abuse - a specialist service is available to survivors of CSA who are experiencing, or who have experienced, domestic violence.

Learning Disability - a specialist counselling service is available to survivors of CSA who have mild to moderate learning disability. Training in CSA and learning disability can also be delivered.

Mental Health - A specialist mental health counsellor is employed to provide support to those who are referred through mental health services.

Newsletter - A quarterly newsletter is produced on behalf of the three sexual abuse agencies in Fife which has a distribution of 3,500 copies via email.

Website – www.kasp.org.uk 38-40 High Street, Kirkcaldy, Fife KY1 1IU

Tel: 01592 644 217 . Email: info@kasp.org.uk

Abigail Robinson

Being a ‘survivor’: what did I learn in order to survive?

To put other people’s needs first/to make myself invisible/to blot out intolerable realities;

To efface myself/to merge with the identities of others/to become the occluded soul;

To internalise my anger, transforming it into fear and guilt/To cut off from my fear, sadness and self-love/To doubt myself/To doubt myself in relation to others/ To avoid intimacy;

To disconnect from and distrust my sexuality/To put myself down, to denigrate my life and my achievements/To act out of self-hatred and a desire to destroy myself/To live in chaos;

To see life as a series of crises to be got through, to see pleasure as guilt-ridden, unreal or untrustworthy’…

What am I learning now, to live my potential?

To put my needs first/To be aware of myself/To be present with my own reality/To assert myself/To experience my boundaries/To connect with and earth my spiritual self;

To stay in my body/To feel and externalise my anger/To feel and express my fear, sadness and self-love;

To trust myself/To trust myself in relation to others/To risk intimacy/To know and trust my sexuality;

To celebrate myself, my life, my achievements/To act out of self-love and a desire for fulfilment;

To live in order and chaos, seeking a balance/Trusting in my own power and open to the flow of life…

To see life as an evolutionary challenge/, to celebrate each day with love, rest, fun
And...Spiritual connection....