THE DAISY NETWORK

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PSYCHOLOGICAL IMPACT FACT SHEET

Premature Ovarian Insufficiency:

From an emotional perspective, a diagnosis of premature ovarian insufficiency (POI) is often likened by the women who experience it, as a grieving process.

For most women who experience bodily changes, the first point of contact is usually their GP.

Depending on their circumstances, the journey from there to diagnosis may be a lengthy one. Medical help in the form of Hormone Replacement Therapy (HRT) is usually readily available but the psychological issues are often either not 'heard' or poorly understood.

There is a difference between spontaneous premature ovarian insufficiency (POI and a Premature Menopause which is the result of a medical intervention eg surgery involving a hysterectomy, radiation or chemo-therapy for life threatening conditions such as cancer, although the former can also be used as an umbrella term for both. For spontaneous POI, cause is most often unknown which can lead to an anxious and unsettling time until diagnosis is established; for a medically induced POI, there is a condition that needs treating and the diagnosis of which is relatively swift, but its side effects (eg POI) often not made clear and often there is insufficient time to emotionally (as opposed to factually) process what might happen next. This makes the psychological impact a little different in each scenario, as will the personal meaning for each individual.

Psychological Implications

Dr Conway, a medical specialist in the field and founder of the Daisy Network, recognised the importance of psychological issues:

"The younger the individual at diagnosis, the more profound the confusion as sexuality, fertility and menopause follow each other in rapid succession. Frequent, initial follow-up and access to a clinical psychologist or counsellor is vitally important in easing the passage through a particularly devastating diagnosis when it occurs in the second and third decades of life."

Infertility, subfertility or secondary infertility, a sense of betrayal/being let down by one's body and feeling out of control, in addition to possibly an increased awareness of mortality/ageing and potential loss of health later in life, are generally unwelcome and unpalatable ingredients hard to digest psychologically, at least initially.

Timing

At under 40 years, this isn't the right time; it's probably different to the experiences of most of your peers and thus "off schedule". POI is life changing, and thus can take time to get you ahead around it, that is to psychological acceptance and adjustment even though your physical health is well catered for.

Infertility, subfertility or secondary infertility

Reproductive status is not a concern for every woman, However, where it is, the loss of the ability to conceive in the traditional way, can be experienced both as a crisis and as chronic

stress. Many find this a particularly painful aspect of POI. In response, they often experience anxiety, isolation and internal conflict regarding their purpose in life with deep implications for sense of self and self- image.

The loss of choice that comes with the word 'infertility' has been described as a crisis that:

> *"Forces persons to deal with a complicated series of losses that hurt deeply, among them the loss of a biological heir, pregnancy, birth, breast-feeding, a life goal, sex-role identity, and self-esteem."*

The pain of this loss, may not go away, thus it is a chronic stressor, and can be exacerbated by societal and cultural norms around the desirability of procreation, which in some cultures at least, is changing. Loss of control in an area considered generally controllable, can undermine a young person's image of herself as a sexual being. This holds true regardless of whether or not she actively wanted a child, has a child already or vaguely thought it might happen some day in the future. One woman with said: '*I feel like damaged goods, no one will want me now'.* While these emotions are real, this does not make them a hard and fast truth, as the stories of many of the Daisy Networkers attest.

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Letting go of a dream or life planThe notion of being child-free can be liberating for some, but for many the loss of a genetically related child can be extremely tough to come to terms with. Children may or may not have been actively planned for, so the transition to a possible child free life, or to build a family using donor gametes (eggs, sperm or embryos), or having a genetically mixed family or one limited in size, can be emotionally bumpy. . Wherever the starting point, letting go takes courage, effort and sometimes additional support.

Vitality

It has been suggested that at any one time a person may be 'working with' four different age levels: their chronological age; their biological age (referring to the state and appearance of their face and body); their subjective age ('*deep down inside, I feel like...*') and their functional age, which is closely related to their social age and their status in society. The loss of fertility for a young woman with POI or premature menopause involves her feelings about her 'femininity', in a society which stresses youthfulness and vitality; women often express fears about "*ageing overnight*". This may be because women feel in an uncomfortable and confusing situation: feeling and being young, while at the same time *feeling* positioned as prematurely 'old' (eg associations with the word 'menopause'). Yet women soon realise that outwardly nothing has changed, and part of the emotional work is to align these two feelings more realistically.

Health

Not only is the person experiencing biological and psychological changes that are not (as yet) the experience of their peers, but the lack of oestrogen at this stage in life does impact other systems in the body and mind, including energy levels, mood, memory and cognition (the ability to think well). The medical recommendation is likely to be long-term use of hormone replacement (HRT) reviewed annually, in order to literally r**eplace** the hormones our body was meant to produce in order to protect bone and heart health. This is often compared to prescribing insulin for someone who has diabetes. It is also true, that there is currently no good hard evidence on the long term effects of HRT use in young women, and this can act as a block to taking it. However, there is evidence that not taking it in these circumstances can adversely impact on future health – a psychological dilemma that can be useful to talk to with your medical provider and others in a similar situation.

Support

Social support for expected life changes tend to be reasonably readily available e.g. advice, information, emotional support (professional and peer), but is less likely for women with POI, particularly at the moment outside of London.

This means that many young women feel quite alone and not well understood. Overall, from surveys by the Daisy Network and others, there seems to be a consensus that the emotional aspects of POI could benefit from being addressed swiftly, at or close to the time of diagnosis, with offers of the same at regular (medical) follow-up.

Status or prestige

The majority of societies still tend to elevate the status of parenthood, thus safeguarding and reinforcing behaviour that relates to procreation and child-rearing. Society's expectation on young girls is usually that they will become mothers. Girls often take 'on board' this expectation, though by no means all, so that they also expect and plan to become mothers themselves.

> *"I feel like I don't belong, like a second-class citizen with no place to go. Without a child, I don't belong in the group with kids who play in the park." (Mahlstedt)*

This loss of this particular status and/or sense of belonging may return in later life, as 'grandmotherhood' may also not be experienced, if not thought about and adjusted to and accepted earlier. However, as one person said, "*POI no longer completely defines me like it did at first; sometimes I scratch at it and it starts to hurt again, but generally it is like a small mark, a part of me but not the whole of my identity*".

Security

For those for whom motherhood was an assumed part of life, the loss of this assumption, along with the expected part to be played in both social relationships and cultural commitments, can leave a young woman feeling hurt and disappointed and less secure in her relationships; although this may or may not be the case in reality. Having children can be viewed as a form of immortality. When the choice is suddenly removed, the security connected to that sense of immortality is lost, which no fertility treatment can entirely reverse. However, others find a sense of immortality in a myriad of other creative enterprises: in helping others, in creating works of art eg books, paintings, music, cooking – you name it.

POI as a Grieving Process

Working with the notion of POI from the psychological point of view as at least in part a grief reaction, sometimes complicated because the losses within it are in many respects intangible, then some factors to consider are:

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a) Circumstances

. POI, whether spontaneous and of unknown cause or a premature menopause the result of a medical intervention or surgical treatment - is an "off-schedule" process or event, relatively sudden, unexpected and unwelcome possibly involving several losses simultaneously.

b) Individual personality and attachments.

This is not easy to assess, as it involves exploring the meaning to the individual, with her particular personality. It could be loss of identity as child-bearer; loss of relationship with the child who is not to be; or loss of expected relationships with others in family and society. For some, it may feel as though a child has actually been lost.

c) Psychosocial circumstances

This covers the woman's support network and includes access, or its lack, to friends, family, cultural and religious support. This may be particularly so in Western society, where expressions of grief for a non-death bereavement or concealed loss is not generally recognised or acknowledged

The First Task - To accept the reality of the situation

Of the losses involved, the one(s) experienced as most profound depends upon an individual's experience, past and present.

The losses can be profound and wide-ranging, but there is little tangible to represent it:.

"The fact that there is nothing tangible to represent the loss actually intensifies the pain and makes the loss more difficult to understand. There is much to cry about, and there is nothing to cry about. Everything is lost, and nothing is lost." (Mahlstedt)

Because of this intangibility, it becomes more difficult to 'realise' consciously and hence the completion of the task of mourning may be more difficult.

The losses explored in some depth above are briefly reiterated here:

- Loss of health
- Loss of status or prestige
- Loss of self-esteem
- Loss of youth
- Loss of fantasy or the hope of fulfilling an important fantasy
- Loss of security
- Loss of relationship with spouse, family, friends, as well as potential child

One person reported

"Many of us even consciously isolate ourselves from friends or family because we come to the point of having to protect ourselves from their platitudes. While withdrawing from others is usually not the answer, we often do so in desperation, when our privacy, our dignity, and self-esteem are threatened."

Physical symptoms take time to bring under control with medication, and it can take time to accept the many aspects of POI.

The Second Task - Releasing emotions

The underlying needs at this stage are those of crisis. Familiar expectations have disintegrated; the person in shock faces feelings of with lack of control and 'incompetence'. Anger often needs to be directed towards something. If unexpressed, it may turn into depression, guilt/self-blame or lowered self-esteem, .

The juxtaposition of wanting to find a cause or something to blame and feeling the blame and the isolation of 'off-schedule' timing, may lead to denial – often thought of as the first stage of grieving. This can lead to social withdrawal and concealment from one's support network. Counselling can provide both a presence and an acceptance of the urge to withdraw as an understandable and normal response in this kind of situation. It can offer support and acknowledgment of the depth of the pain and fear, enabling the individual to grieve as a step towards moving forward.

The Third Task - adjustment

This is unique to each person. There are significant adjustments that may need to be made both to roles within society and family, as well as to self-identity.

A woman who has experienced POI, spontaneously or otherwise, generally can no longer 'naturally' create a family in the traditional way, should she so wish, although there may be a tiny window when this may very occasionally happen..

The word 'menopause' is associated with the ending of a phase of life, a time of ageing and heightened awareness of one's own mortality. This has a psychological impact on young women, even though their condition may differ in that, in the case of a spontaneous POI, they may be subfertile, with very intermittent ovarian function. In young women who have entered a premature menopause as a side effect of a medical intervention, it often helps psychological adjustment to know that they needed treatment to save their life and POI is just an unwelcome side effect. In both cases, there is hope and much can be done,

The Fourth Task - moving on

Task 4 is for many the most difficult to accomplish; either they are not able to loosen the attachments to the lost one sufficiently that new relationships can be formed; or they find the loss process so painful that they become unwilling to risk re-experiencing it. However, most women do achieve this.

There seem to be three main areas to work on:

a) What do I want my new identity to be (including sexual identity, health identity and self-concept)?

b) What place will my potential genetic child continue to hold in my life whilst enabling me to go on and make emotionally satisfying relationships?

c) What do I want those emotionally satisfying relationships to consist of?

Task 4 emphasises becoming active, deciding. Not only does the individual discover what she wishes, but, having done so, she converts that wish into action. For example, HRT has many benefits; one of them, for many, is to increase energy and a sense of wellbeing. However, taking it on a long-term basis carries fears of the risk of breast cancer - are the benefits worth the risks?

If the desire for parenting a child is still strong, then what constitutes the desire may assist in the decision-making process. Firstly, in the case of a couple, is the desire to pass on genes still of paramount importance? If so, then questions of egg donation are raised, whereby male partner's genes can be passed on and the woman experiences giving birth and parenthood. Other options include AID and surrogacy, if the woman is unable to bear a child eg following a hysterectomy. If the desire for one's own genetic child has been let go in both partners, but the desire to raise a child is still present, then the possibilities and difficulties of adoption can be explored. And many Daisy Networks are extremely generous and happy to share their experiences.

Of course for some, the notion of leading a child free life and finding meaning and creativity in ways other than the nuclear family, may be their chosen route.

Conclusion

POI and its psychological impact needs to be considered in its own right. It is more than a health condition focused around reproductive capacity and fears of premature ageing. It provides an opportunity to adopt a healthy lifestyle and realise the value of what one has and can bring to the world.

How to find a counsellor

Should you decide to seek help from a counsellor or therapist, there are several possible routes.

First seek advice from your GP or consultant if you are fortunate enough to be being seen in a specialist clinic. Many practices now have links to counsellors and therapists. In most cases the number of sessions is limited – usually between six and ten but they are generally provided free of charge or you may be asked to pay a nominal sum.

If you wish to go privately, the best way to find a reputable counsellor or therapist is through the British Association for Counselling and Psychotherapy (BACP) or the United Kingdom of Counsellors and Psychotherapists (UKCP), or, if you wish to consider fertility options, the British Infertility Counsellors Association (BICA). A list of providers in your area can be found on their websites. Charges vary according to where you live and who you see.

In addition, your local council or health authority may provide lists of organisations in your area that can provide help, especially if you are on a low income.

It may take time and effort to find a counsellor. It can be a difficult journey but with guidance you can get to a brighter future.

THE DAISY NETWORK

Useful Contacts

British Association for Counselling and Psychotherapy	BACP House, 15 St John's Business Park, Lutterworth, Leicestershire LE17 4HB Tel: 01455 883300 Fax: 01455 550243 E mail: bacp@bacp.co.uk www.bacp.co.uk
BICA (British Infertility Counselling Association)	Contact by e-mail only E-mail: info@bica.net www.bica.net
Relate (National Headquarters) **(On the phone or online, give them your postcode and they will give you centres in your area)**	Premier House, Carolina Court, Lakeside, Doncaster DN4 5RA Tel: 0300 100 1234 E-mail: enquiries@relate.org.uk www.relate.org.uk

Remember that the Daisy Networkers are also available for you to talk to.

Please contact us through the PO Box or by e-mail with your stories, comments or questions.