

**The National Centre for Adolescent and Adult Women with Congenital
Abnormalities of the Genital Tract, Queen Charlotte's & Chelsea Hospital
Du Cane Road, London W12 0HS**

August, 2006

Dear All,

Re: Outcome of the Group Therapy for Women with MRKH Study

Guess what, I came out of HIBERNATION at the end of May¹, having completed the above study. This involved handing in my completed doctoral thesis portfolio, of which the study formed part. However, this did not finalise the work, as I then went on to:

(1) write some papers for publication from it², to ensure that the findings of the study are shared with the larger world out there, rather than this (huge doorstep size) script merely gathering dust in some far flung University library and nobody ever hearing of it again, and thus its contents being lost. Furthermore, in July I

(2) presented the findings to our team at Queen Charlotte's & Chelsea Hospital, particularly considering the lessons learned from it for our clinical practice working with you all, as well as at a psychologist conference in Warwick, and to a group of psychologists/psychiatrists at the Institute of Psychiatry. Added to this, I will be presenting to a group of psychologists at a big conference in Sydney, just after our arrival in Australia, in October of this year. At the end of the conference in Warwick I had people thanking me for allowing them to learn so much about an area that they had little or no knowledge of and felt very moved by, and making this talk the high-light of the conference for them. The feedback at the Institute was similar. Then at the end of July, I (3) had my doctoral viva, which is an oral exam in which I had to defend the whole of the content of my thesis portfolio, including the study and the therapy developed for women with MRKH, the treatment administered and tested for its usefulness. I was asked many questions about it, and at the end the examiners noted that they, again, had learned so much about something they did not know anything about prior to reading the thesis. That it had been so worthwhile and interesting for them, unlike other scripts – dare they say this - which were mostly as boring as they were huge. They added that the work had been pioneering and made a huge contribution to the discipline of Counselling Psychology and that I so deserved my passing.

As you can imagine July was a bit stressful, and actually the whole process of keeping at analysing the findings and writing up was very very hard work, but I kept thinking of all of you and how you were there with me in all of the writing, as well as when I did these presentations or had this viva, **that through me your voices would be heard** by the public who really ought to know, and if I quitted then all of this would come to nothing

¹ following my “disappearance” in November/December

² together with my supervisor and Mr. Edmonds

and would have been in vain and that just was not allowed to happen no matter what came in the way!!!! And stuff came in the way big time, because as you know difficult things just come along without you asking for it, but for good things to materialize you have to work hard for it, to turn the bad into good etc. So that was also what kept me going whatever came my way, and of course the team at Queen Charlotte's kept encouraging me and other special & amazing people, such as my research supervisor, my soulmate husband etc.

Notwithstanding all this, coming out the other end has been exhilarating, and I have been wanting to write to you what the actual outcome of this study is for some time now – but could not find the time to do so, - also to follow up from our therapy groups and our support group meeting which was held early October 2005 on the topic and to meet the promise which I made to you to update you on it all. So here it goes.....

Women with MRKH can have a problematic adjustment to diagnosis:

- (a) When they fail to process diagnosis. This often happens because the information they are given at diagnosis is just too overwhelming and painful to take in and many women shut down at that time, to protect themselves from the sense of threat that they are experiencing being told that they are born without a vagina and womb, that dilator therapy is required to enjoy penetrative sexual intimacy, and that they are not able to carry their own child, but that (now) with the aid of IVF surrogacy, using a carrying mum, they may have the possibility of having their own genetic children etc. As a result their memories of the event are often incomplete, they find it hard to recollect information and when recalled these are often of a sensory nature and there is no coherent story line to it. Added to this being diagnosed at the time that you are, often around age 16/17/18, your thinking has not been able to fully develop and at this age you often still see things merely in black and white terms, without any other shades or colours in between these. Sometimes your family finds it hard to find a balance between giving you space to deal with your emotions, but in the main being supportive, but not giving you the feeling that they are leaving you too it. Or you may come from an environment where expressing emotions is seen as weak, and you do not want to be weak, or mum seems all upset and you want to be strong for her, or nobody wants to let their emotions go, so you decide that it can't be a big deal if no one has any feelings in response, and you feel you should not have any response to it either, whatever, the scenario is. And all of the above things may contribute to you not being able to really digest what has been happening for you.
- (b) Many women interpret diagnosis and its related events in a negative way. A woman may come to conclude about herself that she is different/not a proper woman/a freak. That she is defective/worthless as a woman, outside of female experiences. That nobody will ever want her, that she is unacceptable as a (sexual) partner. That she is unloveable. And that if this can happen, anything can happen and the world is a scary place. Some experience their sense of self and their future as shattered in this.

- (c) Many women try and control the threat to their sense of self as women, and the powerful emotions that they are experiencing following diagnosis, through the use of varied coping strategies, such as making up for their perceived defects by trying to be super-feminine/more than normal/perfect, excelling in a chosen field. Avoiding intimacy, or feeling worthless: becoming a pleaser and being used. Feeling out of control, letting life pass by... Blotting out feelings/memories/ thoughts with drink/drugs/starvation etc.
- (d) What can happen is that over time varied levels of problematic thoughts arise, where the picture of your body, yourself as being feminine, and your MRKH become more and more imbued with negative meaning of being: different, defective, worthless, unloveable etc. Where the view of yourself can become “enmeshed”³ with culturally derived beliefs about what it means to be a woman: where self-worth/value, becomes narrowly linked with the presence of a vagina, the ability to have sex, to have a womb and give birth to children, which will all feed into the ways of coping that you will engage in, to reduce this negative effect. Here the MRKH may become, eventually, to overshadow all of you, where it almost seems to become to make up the whole of your identity, if this makes any sense, and there seems little else that you think defines you.
- (e) The above response is very normal. It is a bit what happens to people when they are being given major diagnosis or like the development of Post-Traumatic-Stress Syndrome following a major negative life event that has an impact on ones’ sense of self, ones’ beliefs about the world/ones’ future in other ways, that are as shattering. So, it does not mean that you are “mad”, responding in the way you do/did.

Now based on all of the above assumptions, I developed this therapy that attempts to help you to revisit the negative life event of being diagnosed, so we can piece the memory back together and the gaps you may have in it, and any misunderstanding that have arisen from it. To consider all your thoughts and feelings about it and make it a bit less scary to look at, and particularly to together identify any unhelpful conclusions that you have drawn from it, and challenge these (see whether these conclusions actually make sense/hold true now). This helps you to build a more positive picture of yourself, where you can take a perspective of a person who is older and wiser than yourself on what has happened, and consider what they would say about this: e.g. would they also have concluded that you are unloveable. To consider the question of what makes a person loveable and acceptable anyway and whether a vagina and womb have anything to do with this. As well as looking at experiences in your life that tell you a more positive story about yourself, discovering more colour, away from the black and white etc. This process aids the acceptance of your condition and yourself with MRKH. Therapy aims to together look at any coping strategies that you are having in order to deal with difficult feelings, that are in the longer term actually harmful, and to try and find other ways of being that are less detrimental both in the short and long run. Therapy looks at relationships and how to go about intimate ones particularly, as well as considering the

³ glued together

losses involved in being diagnosed with your condition, acknowledging these and marking these, and finding meaning in all of the happenings. Specific writing exercises were developed by me to do at home, to then come back and discuss these in the groups, with reading of and learning from hand-outs, trying relaxation and “guided imagery” tapes to reinforce the positive etc. etc.

Then as you know, I looked for women to take part in the therapy outlined above. A group of 39 women came forward. These women were given psychological questionnaires so I could work out what their levels of psychological well-being, their self-esteem were, and how the event of being diagnosed impacted them, as well as how they were coping etc. Then I mixed the group of 39 women, allocating 19 to the group therapy and 20 to a waiting list⁴ in a random process. So having the detail of both these groups of women in terms of how they were doing psychologically, I then split the 19 women into small groups who came for therapy over a series of 7 weekend, whilst the other group of 20 women did not need to do anything. At the end of the 7 weeks, both the small therapy groups, 19 women altogether, as well as those on the waitinglist filled in the same questionnaires again as they had at the start of the study. We had one final therapy session 3 months following that, and women then needed to complete the questionnaires again. Now comparing the questionnaires from before the group, with after the group and at 3 months, I found that the women who engaged in therapy improved significantly in terms of psychological wellbeing, their self-esteem improved, their coping and the initial negative effect of being diagnosed reduced, and these gains increased further from the end of the 7 weeks to follow-up (see Figure 1 on website version of this to illustrate). So much so that comparing the women who had therapy with a group of women who do not have the condition I could not distinguished between the two groups, and at 3 months follow-up the women who had had therapy felt psychologically actually even better than the women who did not have the condition! The women who were on the waiting-list did not change, as expected.

Those who attended the support group meeting in October, 2006 will have heard some of the moving experiences that the groups who took part in the study shared with all of us. Quotes from participant’s experiences of therapy, taken from their goodbye letter’s writings, can be found on the website table 3 (which features this letter, with respective tables appended to them). I have abbreviated and mixed these to ensure that no one can be personally identified from these⁵. The website version also features the poster collages one group of women made. This illustrates with words and pictures what diagnosis was like for them, then what happened in therapy and where they are now following it (with a quote at the end of that as well - table 4). It furthermore has a table (table 1) detailing the process of going through the writing exercises and the change in perspective following challenging negative conclusions drawn about diagnosis. As a whole women reported on how helpful the social support and sharing with other women with MRKH in the groups was in terms of improving feelings of normalness/saneness with a decreased feelings of loneliness, feeling more positive and

⁴ who would have therapy later

⁵ which is something that of course has been ensured during the whole of the study – though obviously those who have taken part in the groups may still recognise themselves in any of these quotes

supported. They noted how the writing exercises helped them to reorganise the muddled memory of diagnosis, where a huge problem was broken down into manageable pieces, made into a smaller monster, that played a smaller role in their life. They noted that the therapy strategies of challenging negative conclusions drawn following diagnosis helped them to discover varied perspectives, different and new dimensions. By coming to understand their thought and feelings and challenging these, the negative image of MRKH and its varied aspects were turned on their head. Women spoke about an increased acceptance of MRKH, where MRKH was not the be and end all, where it could be put in its place, where they could live life to the full... reach out for their dreams and make a difference to themselves and others. They spoke about shedding MRKH as an identity, where MRKH is not them, they are not MRKH, it was just part of them, but they were also much more than that... having the condition did not make them anything of a lesser person, they were as loveable, acceptable as the next person. Women spoke about reducing the power of MRKH where to confront the condition had been to break its power over them. As they came to terms with the enormous significance of this realisation it was like music to their soul. They felt free to break out from the bars behind which they had been trapped for so long, now they could fly... Women spoke about finding meaning in MRKH where they now perceived MRKH as any other syndrome that exists in the world, it was not a parasite anymore. In a way they felt glad to have known, experienced and lived with it, otherwise they also felt they would have been ignorant... It made them a stronger person with a different view of life... They used to be a typical girl who would dream of getting married, having children... but now they have a different vision, they have MRKH, it does not disable them physically, they reprioritise their plans & life; plan other things; enjoy everything more, than had they not had MRKH! They feel they can be themselves, improving and becoming the character they used to be but with also the added one fortified by MRKH! They still can become what they want to become with MRKH alongside them!

The above therapy, though specifically designed to help women adjust to diagnosis and treatment of MRKH, will be easily adapted for use with women with other conditions, such as when (i) young women are diagnosed with their ovaries having stopped working, (ii) are being diagnosed with an absence of ovaries because they were not formed (iii) or other conditions than MRKH that have the absence of the vagina in common, or (iv) when young women are diagnosed with early onset endometrial cancer, when their womb and ovaries have to be removed. All of which have a very similar impact, but need to be tailored to take into account the specific issues associated with these conditions.

I hope to in the future develop the above into a book for all of you and hope to translate the therapy into a web-based package with therapist-guided internet chat groups (which might help women who cannot practically come for the varied therapy sessions, due to distance). The latter might be particularly helpful in countries such as America and Australia, where distances are particularly large.

As to publications of articles and sharing with GP's & Gynaecologists, nurses etc, a rejection of our paper came from both the Lancet (a big medical journal that is read by all sort of medics across the world) and from the Journal of the American Medical Association (another big one), but we are not giving up and are hopeful the British

Medical Journal will accept it. There are other papers that are being rewritten and put forward for publication too in the coming months, so that is all exciting.

Of course, none of the above will happen overnight. I first will need to start focusing on our move, and settling into practice. I was in Tasmania the other day and found a very nice Vet practice for sale, with an upstairs room that I can practice in for both my husband and I, with when you walk out of the door Mount Wellington to the left, and to the right Sandy Bay, but all of this located in a small City!!!. I also spoke to lots of gynaecologists/paediatricians/physicians locally and think a bit of development for women with conditions such as MRKH might not be amiss on the island. Once landed I will also contact the people in Melbourne/Sydney. So lots of scope for me there, as well as of course that I also want to be going back to seeing people with other emotional issues such as depression, eating disorders, other trauma, relational & sexual difficulties, etc. etc. We have been designing our own practice logos, which has been hilarious, burning the night oil to get it into the yellow pages before its Australian deadline, and being generally creative with it.

Now that you have read about the outlined positive result of a group therapy for women with MRKH, and your interest in group therapy⁶ has been aroused⁷, do speak to Davina, the lovely, very capable and approachable psychologist at the Centre, who you might already have met or not met, who has become my successor, when you see her at the next support group meeting, or leave a message with Julie on the answering machine for her to pass on to Davina, or send Julie an email to be passed on to Davina, for her to phone you and discuss what the possibilities are for you etc.

As you know none of this could have happened without your input, the women that I worked with at the Centre, from whom I learned so much about what it is like to be diagnosed with MRKH and treated for it, those who engaged in the group therapy as well as those who I had contact with otherwise in one to one etc. It has been such a privilege working with you all, my life certainly has been enriched by it and I draw from it, and will always carry those experiences with me across the Globe. Though I have left the Centre I remain to have close ties with it, as furthering the cause of women with MRKH, is not dependent on location!!!

Any questions you may have and want to ask me, about the above, or reflections in response to it, do email me on k1m2erley@aol.com. I would love to hear from you. Any further stuff that you want to read up on about the study, is being posted on our website – so do go and visit www.mrkh.org.uk. With my warmest wishes to you all & be in touch!

Jackie

Jacoline Heller, CPsychol.

⁶ or one-to-one therapy as a gentle lead into a group intervention

⁷ or you want a bit of a chat about the issues you are facing

Figure 1: Differences between group CBT and waiting list on the Global Severity Index of the Symptom Check List (SCL-90-R) at baseline, post-treatment and at 3 months follow-up.

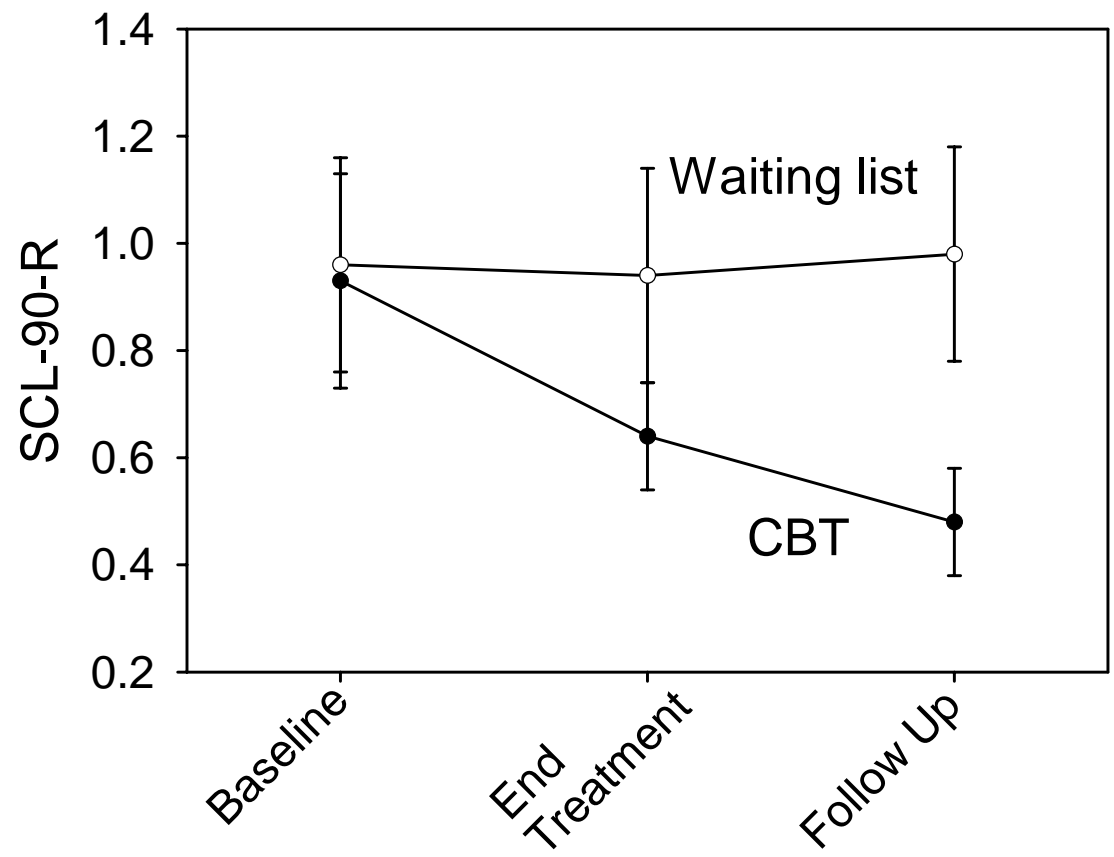


Table 1: Participants' homework writing assignments

<p>Writing Assignment I: Prior to diagnosis</p> <p>'My period became the event everyone was waiting for but never happened. I had the feeling my mum and aunty were discussing it regularly..... I don't remember being terribly concerned. I wasn't ill and all this medical attention seemed to me unnecessary..... It took time for me to be called to have my laparotomy..... I thought this Op would sort it out. I didn't think that what was wrong with me was going to be a problem. I thought that when I woke up I would be normal The next day I would meet the consultant for the last time and go home, NORMAL.....'</p> <p>'My younger sisters had started their periods. I was not worried, I thought periods happen only to some girls and not to others. during the investigations I started worrying that I had some disease and that I will die if I did not have any (periods)..... no one explained.....'</p>
<p>Writing assignment II: Being diagnosed</p> <p>'She walked up to the side of the bed not sitting down to make me or her feel comfortable.....I can't remember my parents being there, but they must as they heard the immortal words which she uttered from her lips " you can't have children, you can't have sex, you don't have a womb or vagina, if you have any questions ask the nurse". Turning on her heel she walked out with a very straight back. I don't remember much else after that about the day.....'</p> <p>'I was numb, and did not hear the rest of the conversation, after the explanation of MRKH, not having an uterus, I was just staring at him and did not ask any questions, and started crying, the whole implication of MRKH became vivid in mind, at that point my world crashed, shattered, broke in pieces. I was unconsolable..... I was devastated.... I just wanted to die.....'</p>
<p>Writing assignment III: Coping with the diagnosis of MRKH</p> <p>'Amongst my friends and then colleagues at work I pretended to everyone that I was normal... During the day I was busy at work, going out in the evening. At night-time lots of questions would enter my head. Why me? Why was I born female, am I female if I can't do what other females do.... How was I going to tell a future husband/partner...I decided subconsciously, I think now, that this was something I could never find answers to, I had to forget it – box it up, go into the world as a normal woman, and believe it wholeheartedly. Never tell anyone not even close friends.... Only mom and dad and perhaps my brother and aunty knew about my embarrassing little problem, the extended family need not know. I felt like I was keeping a secret... keep up the pretence and not let it show..... I could not share my grief and expect sympathy as anyone else would over a broken limb and because no one has ever heard of this condition how do I know that they would believe me anyway. I felt very alone.'</p> <p>'I finished with my boyfriend, I could not see a way of pursuing a relationship, as in my head I kept hearing the doctors words (that it would take a special man to be in a relationship with me). I stopped going out, I stopped eating, I just worked. I exercised to get a perfect body and made myself as pretty as I could, to be accepted, as I felt so rejected..... I had to proof myself and tried to be perfect in every other way, to please, give and be a saint in order to be loved again..... I no longer felt like part of my family, I buried my feelings as they did not know how to support me, it was "harder for my mother to cope, so why was I upset'.</p>
<p>Writing assignment IV: Conclusions drawn about myself, the world and my future</p> <p>'Suddenly the goal-post had been moved. I wasn't what I thought I was. If felt apart form everyone, singular, unique. The world is a place where two</p>

identities meet and reproduce, I was not part of this world. But no one knew this but me. I could move within it unnoticed for what I was. I felt in disguise, someone masquerading as a girl/woman. But inside I felt different. I could not image the future it was a bleak hole....I felt somewhat indispensable....’

‘I was barren, a freak, someone who should not have been born, a miscarriage survived. Everyone would know that I was a freak..... I was unloveable and inadequate.....the plan of marrying and having babies was shattered. I could not have my rite of passage into womanhood, I was both a child and an old woman in one. I now had to walk the path of life alone.....’

Writing assignment V: Challenging unhelpful beliefs and negative conclusions

‘I am still loveable, a bloke can take me or leave me, as I can offer him and the world much, beyond childbearing. I am looking for an advantage in this, working out a future with a different meaning and have much to achieve. This (MRKH) has not changed the character of the person I am, who is caring and responsible, a real fighter and peacemaker for the good of the world. I am being tested, and through this I have become more open minded, wiser, and stronger.’

‘ I ask myself what is the worst that can happen and MRKH is not that bad in the scheme of things. It effects small parts of my life, which I could address if I so wish. I am not sick, I am not disabled, I am not stupid, or ugly, I have eyes and I can see and understand.... and look deeper.....and if others do not that is their problem. I am strong, I can cope with anything. I focus on what is important in my life...look after myself and live life day by day. I do not need to proof myself and relationships I can take or leave. ‘

Table 2: Participants' quotes about their experience of therapy from their 'goodbye letters'

	Effect of Different Treatment Components, Techniques and Processes
Social Support/Sharing	<p>'I feel liberated by discovering that others have had similar experiences and reactions to me. Now I can judge myself less harshly and feel less inclined to hide myself from other people, as I discovered that I am more sane and normal than I thought.Sharing our stories the weight of loneliness has shifted from my shoulders and mind, and I feel more positive, and supported'.</p> <p>'I will miss coming, but I now associate MRKH with this room of people with whom I have forged links and have shared so intimate detail,...To know that you are all out there brings me so much comfort; I will always have you all in my head and draw strength and knowledge from you all, knowing that you are out there maybe feeling similar things.'</p>
Writing Tasks	<p>'What I truly enjoyed and found helpful have been the writing exercises. I express my emotions better in writing than verbally, and by doing so, it has helped me to reflect back on where I have been to where I am now, looking within myself and pulling out more strengths and qualities that I did not think existed, learning that asserting myself is a good thing. Also by writing those exercises, it is something that I can look back on or read when maybe I am feeling low or just need encouragement, a reminder of what makes me a woman!!!'</p> <p>'Through the writing exercises, and discussing these in therapy, I have been provided with a powerful tool that has allowed me to reorganize the somewhat muddled memory of being diagnosed with MRKH.a huge problem has been broken down, making it more manageable, and a smaller "monster" which plays a smaller role in my life than it previously did.....'</p>
CBT Strategies - Challenging Unhelpful Beliefs	<p>'By getting varied perspectives, opinions have been turned on their head, making you consider other issues around it, and discover different and new dimensions. Through the process of coming to understand ones' thoughts and feelings and challenging these, the negative image of MRKH and its varied aspects have been turned round.'</p>
	Impact of Therapy on Patients' Views of Themselves and Their MRKH
Increased Acceptance of MRKH	<p>'MRKH does not need to be the be all and end all of my experiences, or the heavy load that will stand in the way of everything. It can be put in "its place", it need not dominate my life.I will live life to the full, no matter what happens. I can now bring back colour and choices in my life, reach out for my dreams and make a difference to myself and others. Iam more accepting of MRKH, both in my heart and mind.'</p> <p>'I have allowed myself to acknowledge MRKH rather than bury it. Life has made me naturally brave, but now I am being braver by acknowledging that I can have feelings about MRKH and express these. I am learning to "mourn" the choices that I would have faced in a different way had I not had MRKH, mark these, and make choices from those available to me and my husband.'</p>
Shedding MRKH as Identity	<p>'I feel a great sense of relief, more free, facing a future that feels less burdened, brighter; with much shame, embarrassment</p>

	and an “ugly” secret “dispersed”. I now know that MRKH is not me, I am not MRKH; it is just a part of me, but I am also much more than that. I can now see that having the condition does not make me anything of a lesser person, I am as lovable, acceptable, and capable as the next person, and people will like me for who I am..... I can interact with people differently and say “no” when I need to, and be honest about myself to others, I no longer have anything to hide.’
Reducing the Power of MRKH	‘To confront this condition has been to break its power over me. As I come to terms with the enormous significance of this realisation, it is like music to my soul. I am free to break out from the bars behind which I have been trapped for so long, now I can fly....’
Finding Meaning in MRKH	‘I now perceive MRKH as any other syndrome that exists in the world, it is not a parasite anymore. In a way I am glad to have known, experienced and live with it, otherwise I would have also been ignorant.... It made me a stronger person with a different view of life.... I used to be a typical girl who would dream of getting married, having children... but now I have a different vision, I have MRKH, it does not disable me physically, I re-prioritise my plans, life, plan other things, enjoy everything more, than had I not had MRKH! It has enabled me to deal differently with others, I used to be a very passive and wanting to please everybody type of person. I realized that I am harming myself... and decided to stand up for myself, I, literally, do not worry about others’ opinion of me anymore, because I think highly of myself which I never used to do... ... I see things I otherwise would not have seen... I can be myself, improving and becoming the character I used to be but with also the added one fortified by MRKH! I can still become what I want to become with MRKH alongside me!’

Figure 3: Participants' perspectives of their experiences & therapy - Group Vignette Posters – 1



Figure 3: Participants' perspectives of their experiences & therapy - Group Vignette Posters – 3



Table 4: Text to go with participants' collages/posters on the subject of (1) diagnosis, (2) treatment and (3) how they are feeling now:

“What the groups have helped us to do is to (1) stand back and move away from the MRKH and see it as separate from ourselves. This enables us to see how it effects us and has effected us and to take a little more control of it. We can now more objectively analyse and understand MRKH and our journeys and (2) assimilate MRKH and accept it as part of us – not in a violent and destructive or shocking manner, in that it has been forced on us, but in a calmer way, with less conflict and desperation. In a way which makes us feel stronger in the end. These two points may seem contradictory, but in practice they are not – rather they complement and encourage each other. In saying this though, we are not saying we are all perfectly fine now and MRKH is a wonderful asset! We are saying we have gained some kind of insight and a powerful tool to help us learn to live with MRKH, without it taking control of/over us, or even influencing, or playing a part, in every aspect of our lives”.

