

A Glimpse at the Female Experience

This article was written for Positive Women Victoria by Maxine Giourouki in 2013. Maxine is a HARP nurse with the St Vincent's Hospital Melbourne. HARP nurses provide specific support for the management of chronic diseases and complex care needs.

I recently made time to have a good look at our HIV patient database. One of the things I was interested about was our female patient population. The following are the statistics that I came up with were that 25% of our active patients are female and of that 25%, 70% come from a Culturally and Linguistically Diverse backgrounds.

Over the past few months I have been present when medical teams have informed young female patients that they are HIV positive. It is times like this that I am very grateful that Department of Human Services established the Hospital Admission Risk Program (HAPR) roles. I always have a knot in my stomach and feel a degree of anxiety and it is very apparent the Registrars involved feel the same. The reality is that we are well aware that what we are about to tell this young girl is, at that moment, going to rock her world and shatter all her dreams. Once the doctor has given the diagnosis they generally leave and my role has been to attempt to 'normalise' what they have just heard with statements such as:

- *You are not going to die (this one I reinforce)*
- *You are still going to have the life that you have planned*
- *You are still going to meet a wonderful man and fall in love*
- *You are going to get married and have babies*
- *Your babies will not be HIV positive*
- *You are going to dance at your grandchildren's weddings*
- *It is considered a chronic illness like arthritis and diabetes*
- *The treatment in Australia is excellent etc*

When I further explored my list of female patients I considered the confidentiality aspect. Confidentiality is also a priority to discuss at initial contact. When exploring the diagnosis disclosure of the 25% of female patients I broke it down accordingly:

- 19% had told no one (75% CALD)
- 43% had told 1 person only (generally speaking it was their partner and if no partner it was a friend, family member or priest)
- 38% had told immediate family only (generally parents and/or siblings. Often the siblings do not tell their partners)

Unfortunately not one of these ladies would ever consider joining a support group. I have the story of one CALD patient who witnessed one of her friends taking tablets that she immediately recognised as being ART. She was horrified when I suggested that she could have disclosed then that she too was positive. Even after a discussion about the benefits of supporting each other it was apparent that it was never going to happen.

When I initially read the *My Journey Kit* put out by Positive Women my first thought was "I'll have a box full thanks!" I was moved by some of the stories and it also forced me to examine my own

practice and aspects I can improve on. I know already that some of my patients won't take it home for fear of someone finding it, but I am already thinking of ways to get around that.

I have 2 stories that I wish to share about ladies in the first group who have not disclosed to anyone.

A year ago one of my elderly ladies was going overseas for the first time since her HIV diagnosis. I had to spend quite a while convincing her that her HIV diagnosis would not be subliminally stamped on her passport by authorities at the airport as she left the country.

I was recently saddened when one of these young ladies sat in my office with tears pouring down her cheeks telling me about her biggest fear. It is this: that she will die unexpectedly and that 'HIV' would be printed on her death certificate. The implication is that her daughter would then know that her mother was HIV positive. To this lady being HIV positive is the big secret she lives with every day and her plan is to take to her grave without having told a single person.