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INTERVIEW SUMMARY SHEET **Title Page**

Ref. No. C1202/ 17

Wav file Refs: (Administrator use only)

Collection title: HIV in the Family

Interviewee's surname: Grayson

Title:

Interviewee's forenames: Carol

Sex: F

Occupation: nurse and campaigner

Date of birth: GRO-C 59

Mother's occupation: Secretary

Father's occupation: Director of brewery

Date(s) of recording, Compact Flash used, tracks :19/01/07 (tracks 1-3).

Location of interview: Interviewee's home, Newcastle

Name of interviewer: Krista Woodley

Type of recorder: Marantz PMD660 on compact flash

Total no. of tracks: 3

Recording Format: Wav 16bit 48khz

Mono or stereo: Stereo

Burned to DVD(s) (Administrator use only)

Total Duration: 4 hours, 29 minutes, 28 seconds

Additional material:

Copyright/Clearance: see copyright permission form

Interviewer's comments: occasional muffle on microphone

Session One: 19 January 2007
Track 1

Interviewee mentions previous media and campaign interviews, also explains reasons for taking part in project. Brief explanation of husband with haemophilia infected with HIV, Hepatitis B and C, also husband's brother died. Date and place of birth. Describes parents and family background. Primary schools, then secondary school. Describes leisure time outside school. Religious and political background. Educational background: A-levels.
10:00
When left school, worked in library, then for DHSS processing benefits, then worked in Newcastle Polytechnic library. Introduced to psychiatric work and trained as mental health nurse. Then worked in drug and alcohol unit. Meeting future husband, Pete. Travelling with work exchanges, to Russia.
20:00
Experience of haemophilia through working with people with haemophilia with painkiller addiction at drug and alcohol clinics. Husband's experience of stigma in home town when brother died. Husband's ill health when they met; interviewee nurturing him back to health. Interviewee and future husband went backpacking four months after they met. Describes husband's childhood.
30:00
Husband's haemophilia treatment as a child, and attending Treloar's college, Hampshire. Discusses bullying and sexual abuse there. Husband expelled from college, early jobs. Disguising haemophilia from work and school. Interviewee discusses dealing with blood spillages and establishing guidelines for spillages and for informed consent for HIV testing.
40:00
Discusses people who have experienced HIV testing without consent, as part of research for interviewee's MA. Husband's HIV diagnosis in 1985. Describes how HIV got into haemophilia treatment. Advice given to husband at diagnosis. Husband's younger brother's illness and death.
50:00
Younger brother's funeral. Stigma. Incident where neighbours gathered outside family home to protest against them. Future husband's first marriage broke up. Describes telling work that she was involved with Pete, because he had been patient at the unit. Gave up work to spend time with Pete. Value of life experience.
60:00
Backpacking in Mexico. Vaccinations before travelling. Describes travelling through Central and South America. HIV not an issue while away. Discusses early treatment and AZT trial.
70:00
Took haemophilia treatment away with them: interviewee had arranged to have treatment sent out to embassies. Discusses life expectancy. Interviewee's recognition that Hepatitis C might be more of a problem than HIV for husband. Attitudes of haemophilia doctors. Empowering approach to campaigning.
80:00
Discusses sexual relationship and decision not to have children. Discusses natural resistance to HIV. Experience of HIV tests. Plans discussed with partner for interviewee's life after partner died.
90:00
Returning from backpacking. Second backpacking trip with partner's son in Asia. Description of partner's bleed in Nepal. Discusses carrying treatment, very little trouble with haemophilia and HIV while away.

100:00
Reluctance from hospital to teach interviewee how to give partner his treatment injections. Taught by partner in the end. Describes partner's son's experience at school and occasional bullying about father's HIV status. Interviewee discusses initial reaction of friends and family to her relationship with man with HIV. Negative reaction of father initially and later sorting out problems.
110:00
Discusses personal 'baggage' and idea of meeting someone new. New concerns since partner has died. Marriage in local church.
120:00
Involvement in campaigning. Discusses partner being given positive Hepatitis C test result. Working relationship with local media and journalist for publicity.
130:00
Discusses Haemophilia Society and relationships with and funding from drug companies. Discusses early failure to act on information about risks of imported blood products. Blood collected in prisons.
140:00
Discusses implications of paying for blood donations in America. Featuring in local newspapers. Partner's increased problems with Hepatitis C.
150:00
Partner's mother's death and his increasing liver problems. Expenses for campaigning, supporting self on benefits and Macfarlane trust. Setting up their own campaign group with partner.
160:00
Discusses idea of informed choice. Lack of openness about suspect batch numbers and testing. Incident of doctor who wrote article about danger of blood imports. Destruction of important documents by civil servant and subsequently left out of reports.
170:00
Interviewee's own feelings about healthcare system; reluctance to work in system herself, importance of helping from outside system. Respect from healthcare professionals and journalists.

Track 2
Daily life with partner: predictable level of stress. Partner fell and broke hip six months before death. Limits of interviewee's social life. Partner's mother's illness. Interviewee caring for partner and partner's mother. Partner's treatment strike to get synthetic recombinant treatment.
10:00
Discusses HIV blood problems in China in 1990s. Partner's improved CD4 count when he stopped taking haemophilia treatment. Partner going to hospice for first time for an assessment. Partner was in hospice for six months before he died. Interviewee's sudden asthma attack at this time.
20:00
Partner's son during father's illness. Partner's clostridium difficile. Day of partner's death.
30:00
Partner wanted to die in hospice, so was being moved from hospital to hospice at time of death. Describes partner's death. Independent post mortem because of outstanding legal case in US. Partner's brain used for CJD research in Edinburgh.
40:00
Incident of partner having burst vein. Interviewee inquired at hospital for policy for blood spillages around CJD for carers at home. Insurance company couldn't clean carpet because might contaminate machinery. Men in biohazard suits came to take carpet away. Reflects on new friends and how to explain to people what life has been like. Discusses abnormality and normality of everyday life. Describes partner's funeral.

50:00
Funeral arrangements. Partner's brother's organs retained without permission at time of his death and later buried at partner's funeral. Support from family and friends after partner's death. Involvement with Macfarlane Trust. Discusses support for widows.
60:00
Applying for master's course. Talks about value and importance of course to her. MA dissertation focused on global blood trade.
70:00
Desire to see full and independent inquiry. Discusses CJD in blood supply and resulting imports of white cell plasma from US. Talks about David Owen and his support for inquiry. Comparing payments in UK to those made in Ireland. Involvement with Birchgrove and attending events.
80:00
Discusses return to work or doing a PhD. Involvement with asylum seeker groups and activism. Hopes and expectations for the future: travelling, possible future relationships. Reflects on relationship with partner.

Track 3
Interviewee reflects on how she feels at the end of the interview. The value of sharing experiences.
[end of interview]