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THE 'HIDDEN NO MORE' MASS LOBBY JUNE 2010 -
USING ORAL HISTORIES AND CULTURAL
REPRESENTATIONS TO EXPLORE THE
CONCEALMENT OF HUNTINGTON'S DISEASE

JACKIE HARRISON

A THESIS SUBMITTED TO THE UNIVERSITY OF
HUDDERSFIELD IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS

DECEMBER 2013

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All interviewees and questionnaire participants gave consent for their contributions to be used and have approved the use of material quoted.

Finally I would like to thank the Huntington's Disease Association.

List of Abbreviations

APPG - All Party Parliamentary Group

HD - Huntington's disease

HDA - Huntington's Disease Association

HDYO - Huntington's Disease Youth Organisation

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Figure 1 APPG Banner 30 June 2010. Source: the author

Figure 2 Vessie's Pedigree Chart for the Bures Family Group. Source P. R. Vessie, 'On the Transmission of Huntington's Chorea for 300 years'

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Figure 4 Badge featuring the Hidden No More logo and symbol for Huntington's disease. Source: the author.

Figure 5 Hidden No More lobby 30 June 2010. Source: the author. Figure 6 Hidden No More 30 lobby June 2010. Source: the author

Introduction

Huntington's disease is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with Huntington's disease have a 50-50 chance of inheriting the disease. There is no cure or treatment.¹

On 21 March 2011 a banner endorsed by over 700 signatures was handed in to 10 Downing Street. Emblazoned across the banner was the phrase 'HD is Hidden no More'. To most people the letters HD means something they see on their television - high definition - a feature which illuminates and brings clarity, not something to be hidden or kept in the shadows, and so the phrase may on first glance have appeared slightly strange and ambiguous. However, for those 700, HD stood for Huntington's disease and for many of them hiding Huntington's disease had been a very real part of their lives and history.

The signatures were collected when families affected by Huntington's disease, researchers, interested politicians and the media gathered at Westminster on the 30 June 2010 to attend a mass lobby for the launch of an All Party Parliamentary Group (APPG) on Huntington's disease. The group's remit was to raise the public profile of Huntington's disease and give a voice in Parliament to those suffering from the disease as well as to their families and carers. I attended the 'Hidden No More' lobby as I am at risk of inheriting the HD gene. I also care for my brother who has the disease. I lost my mother, uncle and grandfather to Huntington's and felt strongly that it was important to attend the event. The interviewees who participated in the project were also at the event and I have since met them at other conferences. Such

¹ Gene Veritas, 'At Risk for Huntington's Disease', <http://curehd.blogspot.co.uk/> [accessed 20 May 2013].

a relationship clearly has an impact on how I approach the disease as a subject of academic enquiry and I have reflected on my position with regards to Huntington's contained later in this thesis. Whilst my close relationship could have been problematic, in other respects it has also been insightful.

The purpose of this thesis is to study the experience and memories of some of those people who attended the APPG launch and signed the pledge that Huntington's disease should be 'Hidden no More'. The thesis is intended to explore why people attended the event, why they felt Huntington's disease had been hidden in the past and what the impact of this concealment had been. In addition, the thesis analyses cultural representations of Huntington's disease and evaluates whether they have also contributed to the impression that secrecy has surrounded the disease.

The project has used oral histories, which allow new voices and themes to emerge, adding fresh viewpoints to the medical discourse which has dominated much of the research on Huntington's disease. While medical research has increased knowledge about the pathology, genetics, symptoms and potential treatment of the disease, some of the historical medical discourse may well have contributed to the secrecy which has surrounded Huntington's disease in many families.

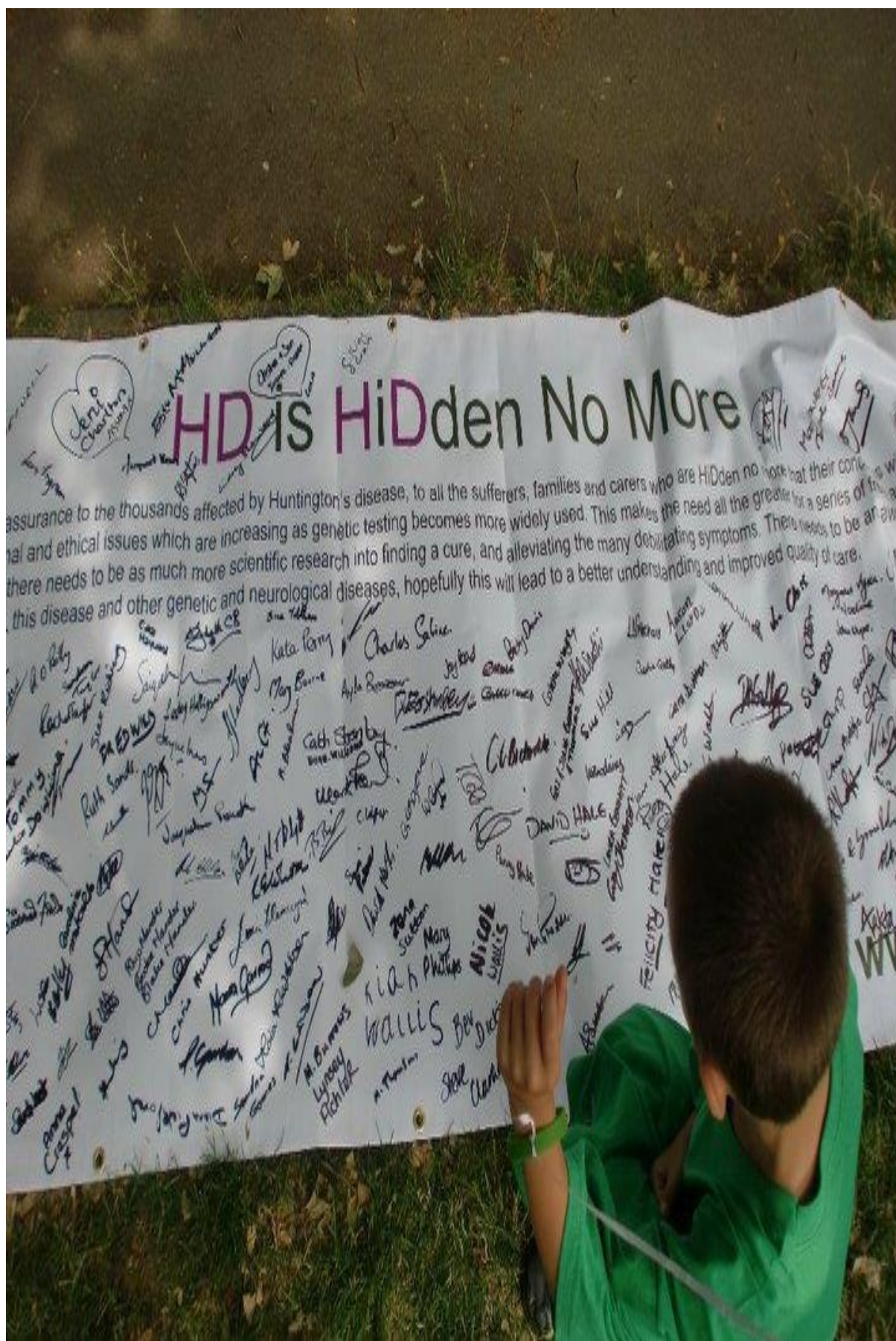


Figure 1 APPG Banner 30 June 2010 Source: the author.

Chapter One: History

Part 1 Huntington's disease: Historical Perspectives

The predominant thrust of work on Huntington's disease has been from a medical view point, with a focus on symptoms of the disease and discussion of the effect on those suffering and the accounts discussed reflect the dominant American and British perspectives.

Though Huntington's disease must have been manifest in past generations it was George Huntington (1850-1916) whose name the disease would adopt. Huntington was the third generation in a line of general practitioners(GPs) in East Hampton, Long Island(US) and his short article of 1872 *On Chorea* would prove to be significant both in its definitive description of the clinical features of the disease as well as its social impact.² Writing for a medical audience, Huntington identified what he viewed as the three 'marked peculiarities' of hereditary chorea:

1. Its hereditary nature
2. A tendency to insanity and suicide.
3. Its manifesting itself as a grave disease only in adult life.³

While modern medicine has discovered juvenile cases of Huntington's, it is nevertheless this paper on the disease that originally presented the case of an autosomal dominant genetic disorder that would continue to attract the worldwide

² George Huntington, 'On Chorea', *Medical and Surgical Reporter*, 26, (1872), pp.317-321.

³ *Ibid.*, p.320.

attention of those studying genetics in general, and Huntington's disease in particular.⁴

Unlike later studies, Huntington did not look at any particular pedigree in detail and he was writing before studies on Huntington's disease evoked the interest of eugenics (the controversial science of improving a population through controlled breeding) which permeates later literature. Nevertheless, Huntington could not fail to acknowledge the shroud of secrecy often assumed when this 'heirloom from generations in the dim past'⁵ appeared in another generation. He did, perhaps with candour, acknowledge medicine's impotence with regards to the disease, noting how many, having seen generation after generation suffer had opted out of formal medical engagement:

No treatment seems to be of any avail, and indeed nowadays its end is so well-known to the sufferer and his friends, that medical advice is seldom sought. It seems at least to be one of the incurables.⁶

Without the genetic transmission it is possible that the disease would have remained a curiosity, however the discovery of its heredity nature put families with Huntington's disease under the microscope of those clinicians with an interest in genetics and increasingly in eugenics. These included Charles B Davenport, who in 1915 published 'Huntington's Chorea in relation to Heredity and Eugenics'.⁷

Published in the United States and writing for a medical audience in the Eugenics records office at the Station for Experimental Evolution, (a centre for eugenics and

⁴ Autosomal-dominant inheritance is a genetic inheritance pattern where an abnormal gene (inherited from one parent) is dominant over the normal gene (inherited from the other parent); the individual shows the characteristics associated with the abnormal gene.

⁵ Huntington, 'On Chorea', p.322.

⁶ *Ibid.*, p.320.

⁷ Charles Davenport, 'Huntington's Chorea in Relation to Heredity and Eugenics', *The American Journal of Insanity*, 73, (1915), pp.195-222.

human heredity research in the first half of the twentieth century). Davenport singled out Huntington's disease for particular scrutiny setting it apart from other illnesses as 'one clear case of a neuropathic entity, the condition known as Huntington's chorea'.⁸ Davenport believed he could trace cases in the United States 'back to some half dozen individuals' and by studying their descendants believed he could define what he termed 'biotypes', measuring the differences in clinical features such as movement and or psychological symptoms, with the whole family being observed and incidents of a range of symptoms mental and physical being recorded.⁹ As a result of his observations he concluded that 'chorea occurs in families characterized by a general liability to nervous and mental troubles'.¹⁰ Following this insight, therefore, it was only a small step towards his advocacy of eugenic measures including 'sterilization for affected members of a family'.¹¹

Two papers followed on from the work done by Davenport, one American study and one British. The focus of both was to trace back pedigrees to what was purported to be their ancestry in East Anglia; both studies introduced links of varying understanding between members of these families and witchcraft.

While also writing for a medical readership in the 1932 *Journal of Nervous and Mental Disease*, P.R. Vessie's study *On the Transmission of Huntington's Chorea for 300 years - The Bures Family Group* takes both a historical and clinical approach, looking back through several groups for the transmission of the Huntington's gene both down through those pedigrees, in England and across the Atlantic.¹² The

⁸ *Ibid.*, p.196.

⁹ *Ibid.*, p.221.

¹⁰ *Ibid.*, p.220.

¹¹ *Ibid.*, p.217.

¹² P R Vessie, 'On the Transmission of Huntington's Chorea for 300 Years -The Bures Family Group', *The Journal of Nervous and Mental Diseases*, 76, (1876), pp,553-573.

language Vessie used was often emotive, to modern eyes at least. Vessie demonstrated how those kin suffering from Huntington's or, as he described them, 'those shot through with the taint,'¹³ were stigmatised. There is even the suggestion that they deserved ostracism rather than empathy and had only themselves to blame for the reaction of society towards them, Vessie stating 'the pity they would receive because of their bizarre dancelike movements is in many cases prevented by their cantankerous behaviour', which 'brings contempt and hatred to their doors'.¹⁴

Vessie evaluated the transmission of Huntington's disease into America as nothing short of catastrophic, suggesting that 'three men and their wives in the group from Bures played the important part in a true American Tragedy'.¹⁵ Vessie was interested in a perceived link between Huntington's disease and witchcraft. He researched and published a pedigree chart of the Bures group which highlighted nine females who were tried for witchcraft and an additional five males for misconduct. Whilst reflecting on 'the spiteful, furious, unyielding nature of witchcraft days,' Vessie nevertheless appeared to be close to suggesting a conflation between those with Huntington's, stating 'it does not require a stretch on imagination, in the light of modern observations in clinic, to comprehend why the classic names witch and hellcat and hag were applied to the unfortunates.'¹⁶ Throughout the study Vessie was also drawing a close link between criminal or antisocial behaviour and those with Huntington's. The effect of the disease as described by Vessie in terms of their increasing isolation is manifest and suggests reasons easily paralleled in the present day as to why many have chosen to conceal the disease.

¹³ *Ibid.*, p.565.

¹⁴ *Ibid.*, p.572.

¹⁵ *Ibid.*, p.555.

¹⁶ *Ibid.*, p.563.

Vessie's summation of the pedigrees studied is derisory but does highlight the way in which those affected came to be framed as different by medical observers, their communities and even within and by their own family:

In the course of three generations of our family, separate groups had begun to inter-marry so freely and prolifically as to form a highly complex genealogy of consanguinity shot through with the taint. Ostracism encouraged this herding, fear forced the isolation of many members, and sensitiveness and memories of ancestral witchcraft, family feuds and politics resulted in the omission of valuable facts from public records... such persistent stupidity of inbreeding and the propagation of a degenerative evolution have contributed to the dooming of many of their descendants.¹⁷

Whilst not proffering eugenic advice *per se*, Vessie cited German studies and reports their conclusions:

After extensive clinical studies in Germany, Enres concluded that it is the duty of physicians to warn all such choreics and the children against propagation, and argues the sacrifice would be negligible compared with the racial injury inflicted by uninstructed and recalcitrant parents.¹⁸

Vessie also discussed the pathology of the disease, though again his language was emotive and subjective, even when discussing the clinical features of the illness. For example he asserted that, 'We shall probably never know the nature of the physical basis for this diabolical evolution'.¹⁹ He thus linked, in his mind presumably as well as that of the reader, a physical illness with something otherworldly, reflecting an additional layer of meaning, misunderstanding and even fear. The final conclusion of the article once again emphasises the perceived historical links between Huntington's disease and witchcraft and in this vein explicitly places the responsibility for transporting the disease to the United States in the hands of

¹⁷ *Ibid.*, p.565.

¹⁸ *Ibid.*, p.565.

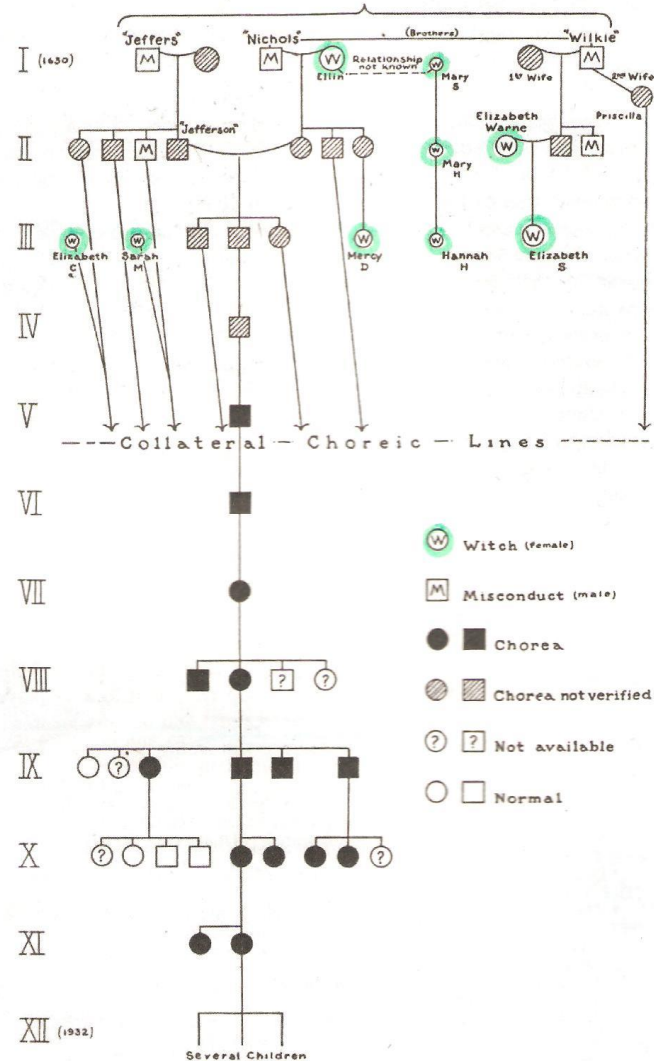
¹⁹ *Ibid.*, p.566.

women, while their husbands are described as 'illiterate and arrogant and none attained recognition or respectability'.²⁰ Vessie knew where the blame really lay:

We suspect their wives of being the lamentable means of transporting a family disease from England to the colonial states... we believe the true story of this lesion to be revealed in the witchcraft trials of women in the Bures group.²¹

²⁰ *Ibid.*, p.566

²¹ *Ibid.*, p.573.



Pedigree chart of the Bures Family Group, showing members tried in colonial courts for witchcraft and misconduct, and the direct descent of Huntington's chorea in later generations.

We are indebted to Dr. Smith Ely Jelliffe for disclosing the collateral families, thus enabling us to trace this group and its background in early colonial archives. Approximately 1,000 cases in these branches were reported by the authors in footnotes 1, 6, 7, 8, 9, 10, 11, 12, 13, 15 and 17.

Figure 2 Vessie's Pedigree Chart for the Bures Family Group source P.R.Vessie, 'On the Transmission of Huntington's Chorea for 300 years', p. 554.

The first detailed British commentary on Huntington's built on the American studies was again written by a clinician for a medical audience. In his 1934 study of '*Huntington's chorea and East Anglia*', MacDonald Critchley was writing as a junior neurologist at King's College Hospital though from 1965 to 1973 he was president of the World Federation of Neurology. Critchley used Vessie's metaphor of the American tragedy and extended the literary imagery adding his view that the story of Huntington's is 'more sinister and far more interesting than anything imagined by American novelist Theodore Dreiser.'²²

Like Vessie, Critchley took both an historical and clinical approach and he used similarly emotive language when describing the disease and those affected.

Critchley, as well as explaining the transmission from one generation to the next, was also of the opinion that all without the gene were affected:

members of the family who are themselves free from the disease, are never the less liable to bear the marks of a grossly psychopathic taint, and the story of feeble mindedness, insanity, suicide, criminality, alcoholism, and drug addiction becomes unfolded over and over again.²³

This sentence demonstrated a profoundly ambiguous approach to the nature and causes of a genetic illness and Critchley was in effect, in one short sentence, declaring those who through no fault of their own had inherited the faulty gene not only as criminal, but also tainted; he later reiterated his hypothesis when he concluded:

Without doubt chorea must have existed even amongst the earliest dependents of the Bures group, and the evidence of witchcraft and criminality must be highly suggestive of a Huntingtonian psychopathy.²⁴

²²Macdonald Critchley, 'Huntington's Chorea and East Anglia', *The Journal of State Medicine*, 42, (1934), pp.575-587. Dreiser wrote a novel entitled *The American Tragedy* published in 1925.

²³ *Ibid.*, p.575.

²⁴ *Ibid.*, p580.

Critchley's article moves on from the Bures group to explore prevalence figures from around Britain, collecting data from both the National Hospital of Neurology and county mental hospital records and interestingly highlights a group in Lancashire noting how:

the presence of these nuclei of Huntington's Chorea in Lancashire again raises the question whether there was any intimate association with witchcraft which was so notorious in that county.²⁵

Like Vessie, Critchley raised the association of Huntington's with witchcraft and appears to assume a link with those with Huntington's and witches, rather than questioning the reactions of others to the strange movements and behaviour often exhibited by someone suffering with the disease.

In the concluding paragraphs, Critchley revisits the advice given by Davenport regarding sterilisation noting that 'Davenport pleaded for 'drastic prophylactic measures, including sterilization'[sic] as well as emphasising the cost of those with the disease to the public purse, for 'sooner or later, most if not all the victims become a public charge'.²⁶

Two longer studies published in the *British Medical Journal* confirmed the dominance of medical discourse about Huntington's. The first, in 1954, was a detailed study of *Huntington's chorea in Northamptonshire*. It was a study of 'pedigrees' and an attempt to estimate the prevalence of the disease.²⁷ Using records from both GPs and mental hospitals, MJ Pleydell collected 8 histories amounting to 61 cases.

²⁵ *Ibid.*, p585.

²⁶ *Ibid.*, p580.

²⁷ M.J. Pleydell, 'Huntington's Chorea in Northamptonshire', *British Medical Journal*, (1954), pp.1121-1128.

Pedigree charts for each group were included as well as a brief clinical description for each individual member, the majority consistent with Critchley's observations were recorded as ending their lives in mental hospitals. Relationship breakdowns and the inability of those with the disease to manage employment and domestic duties are also recorded. The impact on the wider relations, including those not directly affected is also evident. Pleydell notes how

presumably one person who suffers from the disease is more likely to describe other people as suffering from a similar affliction than a person who is free from the disease, since the former does not want to consider that she is the only member of the family suffering from 'nerves' whereas the latter unconsciously opposes any suggestion that there is a family taint.²⁸

The potential of rejection by relations is implicit in these attitudes and thus conceivably a reason to keep the disease secret both within families and from the wider society.²⁹

As well as analysis of the pedigrees, Pleydell also examined patient care and treatments, but it is with regard to health education that his advice became prescriptive and somewhat surprising when one considers the date the article was written in the second half of the twentieth century. Concluding that 'there can be few diseases more distressing than Huntington's either to the patient or to the relatives',³⁰ Pleydell went on to suggest that the inevitable progression of the disease and the autosomal transmission should mean that 'every effort should be made to prevent its spread, and eugenic advice should be given to members of all afflicted families'.³¹ Who should offer this advice is then raised by Pleydell, with practitioners,

²⁸ *Ibid.*, p.1125.

²⁹ Susan Wendell, 'Towards a Feminist Theory of Disability (Disabled People as Other),' in LJ Davis (ed.), *The Disability Reader* (London 1997), pp.271-273.

³⁰ Pleydell, 'Huntington's Chorea in Northamptonshire', p.1121.

³¹ *Ibid.*, p.1121.

district nurses and mental health workers conscripted, as well as the church, for as he observed:

offspring of an affected parent who are of Roman Catholic faith should be advised against marriage; offspring of an affected parent who are of Protestant faith should be advised not to have children[...]the help of all churches would be of great help undertaking these measures.³²

A further similar study was published in the *British Medical Journal* in 1962, in which Lyon observed 'Huntington's chorea in the Moray Firth Area'. It examined seven 'pedigrees' and is once more written for a medical audience. Like previous studies it also focussed on a particular geographical area and is of particular interest due to its recognition of the isolating impact of Huntington's disease. As Lyon noted, 'it is hoped to illustrate how the disease can remain localized[sic] so long as it is confined to a closed community'.³³ Like the Northamptonshire study, symptoms are analysed and admission to mental hospitals listed. The study also explores the impact of Huntington's on such societal norms as marriage; the nature of the fishing community had meant that marriages had often taken place within the community and records were available.

One woman is recorded as declaring that she 'made her children promise never to marry'.³⁴ Another 'started inquiring about the advisability of her own marriage'³⁵ and Lyon concludes that 'a girl from an affected family would have a poorer chance of matrimony'.³⁶ This exclusion from customs such as marriage may reasonably offer a

³² *Ibid.*, p. 1128.

³² LL Rae & MD Lyon, 'Huntington's Chorea in the Moray Firth Area,' *British Medical Journal*, (1962), pp. 1301-1306.

³³ *Ibid.*, p.1301.

³⁴ *Ibid.*, p.1303.

³⁵ *Ibid.*, p.1303.

³⁶ *Ibid.*, p.1303.

reason the disease was effectively hidden within families. Lyon did not go so far as to advocate a eugenic agenda, although it is noteworthy that examples of people who chose not to have children are prominent. Lyon's concluding remarks were to give thanks to the doctors who helped with the work and made records available, significantly he also thanks a variety of other medical professionals emphasising the dominance of medical professionals rather than family members in the compilation and analysis of information.

A letter to the *British Medical Journal* in 1968 suggests such views were a continuing part of the mainstream discourse in the late twentieth century. J E Oliver is critical of the absence of accurate recording and advocates a medical linkage system to identify occurrences critical of what he termed 'the enfeebled attitude to the question of birth control, sterilization [sic] and as a last resort termination of pregnancy'.³⁷

Oliver supported Pleydell's recommendations explaining:

My experience is the same as that of Pleydell; in general members of these unfortunate, drifting families welcome sympathetic but decisive help in preventing them having large numbers of children.³⁸

Oliver's conclusion here echoes that of Pleydell and similarly placed the whole family affected or otherwise under scrutiny. In a longer paper written in 1968 Oliver examined what he termed 'Six Generations of ill-used Children in a Huntington's; pedigree', Oliver concluded that 'very frequently all the children from these families showed anti-social tendencies in adult life'.³⁹

³⁷ JE Oliver, 'Abortion and Huntington's Chorea', *British Medical Journal*, (1968), pp.576.

³⁸ *Ibid.*, p576

³⁹ J, E Oliver & K Dewhurst, 'Six Generations of ill-used children in a Huntington's Pedigree', *Postgraduate Medical Journal*, 45, 530, (1969), pp. 757-760.

This unwitting reiteration of the dominance of medical discourse in relation to Huntington's disease absents entirely the voices of those affected. Few of these studies feel any need to present the reader with an idea of lives lived prior to the illness or the feelings of those with the disease.

New voices.

A challenge to the dominant medical discourse did eventually come, as recently as the final decade of the twentieth century, from historian Alice Wexler in two books and several articles about Huntington's disease. Her first book, *Mapping Fate*, juxtaposes the breakthroughs in the scientific research which led to the discovery of the faulty gene (that if inherited will lead to certain onset of the disease) with her own story, that is of someone at risk of inheriting the gene, with the effect of Huntington's disease on her family. The result, she writes was 'considered a shameful secret and we did not discuss it except with close relatives and then only rarely'.⁴⁰ The secrecy and shame analysed by Wexler and the concealment of the disease in families right up to the latter part of the twentieth century is a crucial theme, central to the oral histories of those who attended the APPG launch, declaring on their banner that they would be 'Hidden no More'.

Wexler departs from the medical literature discussed previously, with its relentless focus, like the microscopic examination of microbes in a petri dish, on the scrutiny of medical practitioners and instead looks to explore the 'collateral damage' of Huntington's on the wider family by narrating her own experiences; adding memories and new voices to the dominant medical discourse. Wexler pursued this theme further in her next book, *The Woman Who Walked into the Sea*. She revisits East

⁴⁰ Alice Wexler, *Mapping Fate* (California, 1995), p.11.

Hampton, the town where George Huntington first encountered families with the then unnamed malady and re-evaluates the work done by Vessie, Critchley.⁴¹ Wexler is critical of much of their research though she acknowledges the irony that work by eugenic propagandist Muncy has provided useful data and aided her own research. In fact, Wexler looks upon eugenics as a vital lens through which to study the history of the disease. She also explores the stigmatisation of those with Huntington's disease and their ancestors; the associations in the work of Vessie *et al* with criminality and feeble mindedness, for example. The supposed association with witchcraft is also examined and left discredited by Wexler albeit with some surprising reactions. Exploring the history of witchcraft and Huntington's disease, she found that while Vessie's thesis has been discredited today not only does it still circulate but the reaction of some is one of disappointment when they learn this.

When I tell members of families affected by Huntington's that the witch story has no historical foundation, some are disappointed as it served as a metaphor for their feelings of being isolated and misunderstood.⁴²

Wexler's work therefore both re-evaluates much of the historical literature on Huntington's and opens up new avenues for exploration. She began the process of telling the stories of some of those absent from the history of their own condition in the past, and although this approach was not without its problems; the sensitivity of the material meant that Wexler did initially want to change the names, even though no one in this history was still living. *Stigma, History and Huntington's disease* is a bold challenge by Wexler to so much of the medical discourse in the past; a

⁴¹ Alice Wexler, *The Woman Who Walked into the Sea* (Yale, 2010).

⁴² Alice Wexler, 'Stigma History and Huntington's Disease', *The Lancet*, 376, (2012), pp.18-19.

revisionist attack upon received attitudes towards those with Huntington's and their relatives and the associated secrecy that many felt compelled to observe.

In an unambiguous manner Wexler holds to account the medical profession for its part in generations of disapprobation suffered by victims of Huntington's disease D. She affirms her opinion that narratives by such as Vessie and Critchley 'undoubtedly played a part in strengthening hostile perceptions of families with Huntington's disease, within medicine as well as outside it'.⁴³ To underline her point further she continues that, 'The secrecy and denial common even today among Huntington's disease families is partly a legacy of eugenics in the past as well as a response to stigma and discrimination in the present'.⁴⁴

Following Wexler a new evaluation in 2010 of the historical link between Huntington's disease and witchcraft has been offered by Loi and Chiu.⁴⁵ In a similar vein to Wexler, they review the work of Vessie and Critchley and are critical of it, arguing that it involved more than a suggestion of negative gender bias:

The history of Huntington's disease demonstrates the influences of thinking of the times, first targeting women who 'behaved badly' and the branding of them as witches in the seventeenth century, and then discrimination towards those with strange and unknown diseases, such as Huntington's disease.⁴⁶

The history of prejudice, stigma, shame and isolation, fuelled rather than quelled by the very practitioners closest to it, goes some way towards presenting a clear demonstration of the significance in 2010 of the launch of the APPG and the adoption of the banner 'Hidden No More'. Some who may have experienced

⁴³ *Ibid.*, p.19.

⁴⁴ *Ibid.*, p.19.

⁴⁵ Samantha Loi & Edmond Chiu, 'Witchcraft and Huntington's Disease: A Salutary History of Societal and Medical Stigmatisation', *Australasian Psychiatry* 20,5, (2012), pp. 438-441.

⁴⁶ Loi & Chiu, 'Witchcraft and Huntington's Disease: A Salutary History of Societal and Medical Stigmatisation', p. 439.

discrimination in the past and those who still faced isolation in the present were able to unite and gain the strength to challenge these issues at both a personal and political level. Nevertheless, the primacy of the historical medical discourse and the attitudes transmitted have continued to shape how Huntington's disease has been viewed, though new voices are increasingly challenging this dominance. A new discourse is beginning to emerge which includes family voices and experiences rather than merely the medical perception of the past.

Part Two: Madness and disability.

Psychiatric symptoms are a recognised major aspect of Huntington's disease; whilst the jerky and dance like movements of someone with Huntington's disease are easily perceptible, the effect of the psychiatric symptoms are often at least as disturbing and disabling. Throughout history, for many sufferers it was the psychological symptoms of the disease that ultimately led to confinement and end-of-life care in asylums and mental hospitals. Yet, while it is a verifiable fact that many people with Huntington's disease were recorded as patients in these asylums, many works on madness and asylums produces nothing but a void; an absence where Huntington's disease should be, in studies of madness and the histories of these institutions. Of course difficulties in diagnosis and the continued secrecy may account for some of the gaps.

Studies of Huntington's disease confirm that asylums must have contained many sufferers of Huntington's disease we need look no further than Pleydell, who used GP and asylum records to trace seven Huntington pedigrees and details the histories. Pedigree one begins as follows

I 1:- Died in the Northamptonshire asylum; the cause of insanity is not recorded.

II 1:- Suffered for Huntington's chorea and died in the asylum at the age of 53.

III 1:- Age of onset of disease not known; death aged 40.⁴⁷

This litany of early death often in asylums continues for almost seven pages. These pedigrees gave a number, an age and place of death and some outline behaviours and symptoms, one for example whose:

mental deterioration became more and more marked until at last his unkempt appearance and his curiosity in the opposite sex necessitated his removal to a mental hospital.⁴⁸

For women the threshold for commitment to the asylum was a little more prosaic, Pleydell noting how a woman was 'admitted to a hospital two years ago as she was unable to manage her domestic duties'.⁴⁹ Pleydell did discern that 'domiciliary care obviously was preferable to institutional supervision', but identified a range of symptoms and behaviours such as anti-social behaviour and mental instability that often made that home care impossible.⁵⁰ In addition Pleydell hinted, perhaps unwittingly, at a class basis for the treatment and perception of those in asylums. Noting that whilst many with Huntington's often experience 'a fall in the standard of living and the social class,' he nevertheless thought it probable that 'patients from the professional classes can be cared for longer in their homes'.⁵¹ The Northamptonshire study is echoed in a paper by Rae and Lyon Huntington's Chorea

⁴⁷ Pleydell, 'Huntington's chorea in Northamptonshire', p.1122.

⁴⁸ *Ibid.*, p.1122.

⁴⁹ *Ibid.*, p.1125.

⁵⁰ *Ibid.*, p.1126.

⁵¹ *Ibid.*, p.1126.

in the Moray Firth area of the Scottish Highlands, and similarly lists the 'mental asylum' as the place where many sufferers spent the end of their lives.⁵²

These pedigrees give scant detail or clue to the lives those with Huntington's led before they appear as a dot on a chart or a number on a list. Yet a couple do stand out, each of whom were soldiers. One 'enlisted in the first world war with little regard whether he was killed or not and was decorated three times', and another who was aware of Huntington's disease's hereditary nature "enlisted in the first world war caring little whether he was killed or not' was decorated twice".⁵³ Yet these heroic sufferers' tales are few and these infrequent accounts serve to reinforce the perception of the prevailing narrative; one of odd and challenging behaviours, which further isolated the sufferer and their close relations from wider society and ultimately led to permanent isolation in asylums.

Having established the prevalence of Huntington's in asylums, the question then arises as to where the accounts of these patients are amongst the secondary literature on madness and asylums? In fact there is little or no reference to Huntington's despite those writing about Huntington's disease, Critchley for example, using county asylum records as a resource for research when studying Huntington's. This gap in history of 'madness' throws up the intriguing possibility that Huntington's was a disease that not only required itself to be hidden from society as a whole but it was also an irritating exception to the dominant discourses on the treatment of 'madness' from the nineteenth century onwards. Notions of rest and calm, cure and indeed asylum itself did not fit easily into the pattern of Huntington's with its inevitable relentless decline into an agitated, deeply disturbing end. It is of course as

⁵² Rae & Lyon, 'Huntington's Chorea in the Moray Firth Area', p.1304.

⁵³ Plydell, 'Huntington's Chorea in Northamptonshire', p.1121.

impossible to prove a negative as it is to ascribe thoughts and opinions to those long dead who did not directly express them, but it must be reasonable to conclude that there was certainly little disincentive not to keep Huntington's disease hidden away even within the machinery of the asylum system itself.

This notion of a dichotomy between asylum in its broadest context and containment is supported by Michael Foucault. The experience and treatment of the insane throughout the ages and the rise of their management in asylums is charted by Foucault in his study *of Madness and Civilization*.⁵⁴ From the wandering itinerant mad on their metaphorical 'ship of fools' to the confinement in the new asylums such as Pitié-Salpêtrière Hospital in Paris and Tukes' Retreat in York, Foucault evaluates the changes in the treatment of the insane and the rise in psychiatric medicine. Often critical of the asylum, Foucault's prevailing idea that confinement of the mad in asylums was containing rather than curing finds a strong resonance in the Huntington's experience, the records showing how many of those with Huntington's spent the ends of their lives in asylums. The pathology of the disease however and its degenerative course meant there was little that could be done to treat Huntington's patients. Porter views some of Foucault's ideas as 'simplistic and over-generalised', yet in any discussion of madness and asylums as spaces for remedy and recovery, patients with Huntington's would be problematic since its degenerative course left sufferers without any useful treatment or cure.⁵⁵ Nevertheless, it would be in such places that many of those with Huntington's spent the last part of their lives.

An augmented analysis of the lack of treatment and cure for many conditions affecting those in asylums is considered by Roy Porter in *Madness: A Short*

⁵⁴ Michel Foucault, *Madness and Civilization* (New York, 1988).

⁵⁵ Roy Porter, *Madness: A Short History* (Oxford, 2002).

History.⁵⁶ Whilst he does not mention Huntington's *per se*, Porter does highlight the increasing use of asylums for a range of illness with little hope for treatment, including those with:

Degenerative neurological disorders who were increasingly shepherded through asylum gates. For all such conditions the prognosis was gloomy, and the asylum became a dustbin for hopeless cases.⁵⁷

Porter also discusses the increased interest in heredity and insanity and the use of the asylum as society's hiding place for those considered undesirable, a place where those suffering could be shut away 'and prevented from breeding recidivists and imbeciles'.⁵⁸

Looking further into the past, Porter explores the path, already familiar from Vessie's work, which linked madness and witchcraft. The impact on the wider familial group is also deliberated in, noting that 'Insanity was deeply shameful on account of its overtones of diabolical possession or a bad stock'.⁵⁹ What is clear from Porter's work is that stigma and shame went hand-in-hand with insanity and for insanity we can read Huntington's too; neither professionals nor the general public were inclined to make much of a distinction. Huntington's stigmatising effect on the sufferer and therefore by inevitable extension the whole family is all too apparent in much of the secondary literature reviewed and illustrates the pressures that led inevitably to the literal hiding of sufferers in asylums as well as an unspeaking metaphorical concealment, a conspiracy of silence within families.

⁵⁶ Porter, *Madness: A Short History*, p.93.

⁵⁷ *Ibid.*, p.119.

⁵⁸ *Ibid.*, p.119.

⁵⁹ *Ibid.*, p.90.

It is possible to find literature on madness where Huntington's makes an almost ghostlike appearance, unnamed and unspoken as yet, but the familiar tropes point us inevitably in the direction of Huntington's disease. In *Mystical Bedlam*, McDonald quotes a description of a patient that is highly suggestive of persons displaying symptoms of Huntington's disease, the movements caused by Huntington's are once again associated with witchcraft or possession: 'Jerking 'helplessly like a marionette controlled by a careless puppeteer was to the popular mind a strong reason to suggest witchcraft'.⁶⁰

Gilman in *Disease and Representation* also examines such 'mad' behaviour and discusses it in the context of what he considers 'the construction of the image of the violent insane'.⁶¹ Where Huntington observed a man with chorea relentlessly pursuing young women and Critchley and Vessie associated Huntington's disease with societal perceptions of witchcraft and criminality due to the lack of control someone with Huntington's has over their body and behaviour, Gillman's summation is that 'the mad are unable to control their own actions, limbs waving wildly, slavering and most importantly violently aggressive'.⁶²

Cohen's exploration of *Family Secrets Living with Shame from the Victorians to the Present Day* narrates a collection of histories, the most pertinent being those relating to the treatment of children with learning difficulties and other disabilities. While Huntington's is for the most part a disease that affects adults in middle age, parallels

⁶⁰ Michael McDonald, *Mystical Bedlam: Madness, Anxiety and Healing in Seventeenth Century England* (Cambridge, 1981), p.209.

⁶¹ Sander Gilman, *Disease and Representation: Images of Illness from Madness to Aids* (Cornell, 1988),

⁶² *Ibid.*, p. 12.

can certainly be drawn, not least as it contends that children were placed in asylums 'to conceal the disgrace of a tainted bloodline'.⁶³ In this case it is the children who cast doubt upon the health and mental soundness of the family and endangered their siblings' prospects in marriage, 'Families that had been pitied became families to fear'.⁶⁴

This broader literature on madness places Huntington's in a context where madness and insanity was observed, classified, scrutinised and treated often in asylums away from the close relations and importantly away from wider society. Andrew Scull's update of his 1979 text, titles his work on madness and society on Britain 1700-1900, *The Most Solitary of Afflictions*.⁶⁵ This definitive and comprehensive account of 200 years of incarceration, shame and despair contains no mention of Huntington's leading to the conclusion perhaps that Huntington's disease has truly been the most solitary of afflictions. Themes emerging from these secondary studies evaluate the position of the sick and disabled as different and demonstrate how having a relative in an institution could isolate and stigmatise the whole family. As most affected by Huntington's had one or even several relatives in an asylum, the themes in wider secondary literature on madness and asylums reflect the themes which emerged in the medical discourse on Huntington's disease.

⁶³ Deborah Cohen, *Family Secrets: Living with Shame from the Victorians to the Present Day* (London, 2013), p.111.

⁶⁴ Cohen, *Family Secrets: Living with Shame from the Victorians to the Present Day*, p.111.

⁶⁵ Andrew Scull. *The Most Solitary of Afflictions: Madness and Society in Britain 1700-1900* (Yale, 2005).

Chapter Two: Cultural Representations of Huntington's disease.

The history of Huntington's' disease representation has been one of an ambiguous shifting relationship between societal stigmatisation and medical perspectives, treatises which while aimed at professionals never quite seemed to try very hard avoid the stigmatisation and aversion they chronicled. It is no surprise therefore that given the prominence our society attaches to medical discourse it has thus far shown itself to be a principal thread running through the means in which Huntington's disease has been represented in literature. The repetition of perspectives running though older medical literature of rumour and superstition have persisted, repeated in cultural representations such as literary fiction which reaches audience's beyond the readers of specialised medical journals. The value in analysing cultural representations of Huntington's including those in literature, television and print media lies in their ability to both reflect and influence the way Huntington's disease is understood by the wider society. They also reveal changes in the discourse surrounding Huntington's disease, and while it is still predominantly written about and discussed in medical journals these, first person narratives and fictional representations demonstrate how some of the attitudes towards those with Huntington's in the past still persist.

Part 1: Literary Representations.

Literary history, Lennard Davis affirms, is peppered with characters with various disabilities, he notes the frail Tiny Tim in *A Christmas Carol* and Hippolyte, the

clubfooted stable boy in *Madame Bovary*.¹ Characters with Huntington's disease have also appeared in literary texts and these representations sit alongside a rich history in literature of characters with a wide spectrum of physical and mental illness and disability. However wide the range of maladies depicted in literature may have been, the treatment of disease and disability has often been as narrow as the range of illnesses has been eclectic. Disabled characters are generally set up as different from the 'normal' characters in the novel, signifiers of whatever metaphorical malaise the author wishes to convey, as noted in the *Disability Reader*. 'Literary and artistic works show disability by means of a number of common images – disabled persons are portrayed as criminals or monsters or as people who are suicidal, maladjusted or sexually deviant.'² The critically-acclaimed novel *Saturday* by Ian McEwan illustrates this point well; the central character Baxter whom the reader discovers has Huntington's disease is ascribed all of the facets described above.³ By expanding these stereotypes, McEwan harks back to the medical discourse surrounding Huntington's disease. The novel was well received by literary critics, but a short review in the *Journal of Neurology, Neurosurgery and Psychiatry* noted how 'McEwan draws upon an association of Huntington's disease with social neglect and criminal behaviour', a social aspect of the disease that had already been accentuated by Vessie and Critchley some eighty years earlier.⁴

A review of the novel appeared in the *Lancet*, written by Michael D. Rawlins and Nancy Wexler. It is critical of the book and the way 'McEwan sadly reinforces the stigma and stereotypes from which persons with Huntington's disease suffer, and

¹ Lennard Davis, 'Constructing Normalcy,' in Davis L (ed.), *The Disability Studies Reader* (London, 1997), p.101.

² *Ibid.*, p.78.

³ Ian McEwan, *Saturday* (London, 2006).

⁴ Hendrick Voss 'The Representation of Movement Disorders in Fiction', *Journal of Neurology, Neurosurgery and Psychiatry*, 83 (2012), pp. 994-9.

which make them hide both their inheritance and their destiny'.⁵ In his use of these old tropes, McEwan demonstrates the immense influence cultural representations can have on the continuing secrecy around Huntington's disease.

The *Saturday* of the title refers to the day of the anti-Iraq war demonstration on 15 February 2003 and this protest provides the backdrop for the events of the novel to unfold. Baxter is introduced to the reader after a car accident with the central character Perowne, an off-duty neurologist. An altercation follows and Perowne soon deduces that Baxter has Huntington's. The juxtaposition between the powerful Perowne who appears to have it all, -home, career wife children- is drawn in stark contrast to Baxter's chaotic life. This sets up the central tension in the novel which peaks when Baxter breaks and enters into Perowne's home and disrupts the calm within. The imagery McEwan uses to describe Baxter is stark yet redolent of the medical texts of a century before: 'the shadow of a strong beard adding to the effect of a muzzle. The general simian air is compounded by sloping shoulders'.⁶ This infers that Baxter is less than human and thus something to be controlled. Davis assessed this link between disability and animal in other literary texts and concluded that 'to have a disability is to be an animal'.⁷ McEwan is clearly intent upon extending this conceit.

McEwan, through Perowne, also touches on the secrecy and hiding of the disease as he confronts Baxter with his diagnosis in order to gain the upper hand in the

⁵ Nancy Wexler & Michael Rawlins, 'Prejudice in a Portrayal of Huntington's Disease,' *The Lancet*, (2006), pp. 169-170.

⁶ McEwan, *Saturday*, p. 88.

⁷ Davis L 'Constructing Normalcy', p. 20.

argument, 'Perowne is counting on Baxter knowing about his condition. If he does, he won't have told Nigel or Nark or any of his friends. This is his secret shame.'⁸

In the final scenes of the novel, the calm of domestic life is shattered by Baxter wielding a knife. Assuming a reader who can only see horror and shame in Baxter's condition, McEwan echoes those who wrote decades earlier of soldiers caring nothing for death, Baxter is 'a man who believes he has no future and is therefore free of consequences[...] determined to take revenge for the perceived humiliation earlier in the day'.⁹ Nevertheless, Perowne takes control by offering the false promise of a place on a medical trial; a man with a worthless life has been offered, however spuriously, some reason to live. The understanding implicit between reader and author is that, in making this offer Perowne retains his position of power and maintains it when he decides not to pursue charges, reasoning that 'Baxter has a diminishing slice of life worth living, before his descent into nightmare hallucinations begins'.¹⁰

The representation of Huntington's disease in McEwan's novel, while clinically accurate, includes problematic stereotypes of criminality, anti-social behaviour, and animalistic metaphor. McEwan had clearly done his research, leaving little out from the litany of nineteenth and twentieth century accounts. Such attitudes, albeit in a fictional work, reveal how cultural representations could influence or reinforce a reader's perception of someone with Huntington's. The novel also reveals McEwan's

⁸ McEwan, *Saturday*, p.94.

⁹ *Ibid.*, p.210.

¹⁰ *Ibid.*, p.278.

probable immersion in the attitudes which prevailed in the historical medical discourse.

Like demonstrators on the Saturday of McEwan's novel, Huntington's disease families also travelled to London in June 2010, to engage in the political process and challenge some of the attitudes that have contributed to the concealment of the disease. McEwan unwittingly betrays various prejudices and easy assumptions in his construction of the Baxter character in this novel, demonstrating the extent to which shorthand stereotypes, arguably reinforcing rather than challenging perceptions of those with Huntington's disease, were extant in 2010.

In addition to McEwan's *Saturday*, the illness has appealed to several authors, no doubt attracted by the transgressive appeal of its symptoms and historical associations. Characters with Huntington's appear in Barbara Vine's *The House of Stairs* (1988), whose narrator is at risk from the disease, and Robert J Sawyer's *Frameshift* (1997), a science fiction page-turner where the central character learns about his risk at a meeting with his biological father.¹¹ Kurt Vonnegut's novel *Galapagos* (1985), also makes creative use of Huntington's; describing how two characters, the brothers Von Kleist, anticipated inheriting the disease, how 'they had been expecting to go crazy at any moment to start dancing and hallucinating for twenty years'.¹² By good providence, the brother without the Huntington's gene becomes the father of the evolving and defective gene-free human race, though not as we know it-the faulty gene this time serving nicely as a metaphor for the entire culpabilities of humanity as a species.

¹¹ Barbra Vine, *The House of Stairs* (London, 1989); Robert Sawyer, *Frameshift* (New, York 1997).

¹² Kurt Vonnegut, *Galapagos* (New York, 1994).

Hendrick Voss considers representations in fiction as having several functions. He argues that for Huntington's in particular, both *Saturday* and *Frameshift* could serve a 'medical function' in literature, 'marking new medical views or the elucidation of medical knowledge via literature'.¹³ Although a closer analysis of *Saturday* supports a view that whilst the clinical and medical information is detailed the attitude of McEwan to the character of Baxter is closer to what Voss terms the 'literary function' of these representations. That is where 'the majority of patients with movement disorders will have been confronted with the stigmatising effects of the disease authors conversely use movement disorders to underscore a person's ridiculousness, isolation or his position as maverick'.¹⁴ Thus demonstrating how fictional representations may, just as easily, add to rather than challenge the stigma encountered by those with Huntington's disease, especially given the raw historical material provides such easily presentable drama

Part Two: Huntington's disease on Screen.

Television representations are more common than in film, perhaps because the nature of Huntington's does not fit neatly into the scope of a 90 minute feature film. Television dramas and soap operas have a longer time frame to explore the challenges of the disease, though, as Huntington's disease can take fifteen to twenty years to progress from diagnosis to death, it is seldom suited to either film or television. When Huntington's is portrayed on television the representations are often

¹³ Hendrick Voss, 'The Representation of Movement Disorders in Fictional Literature', *Neurology, Neurosurgery & Psychiatry*, 83, (2012), pp.997.

¹⁴ *Ibid.*, p.997.

either sensational or inaccurate, with the genetic test done overnight in contrast to the six months plus counselling that precedes it in reality.

Representations of Huntington's disease in soap operas and medical dramas are relatively common. The drama *Doc Martin* featured a Huntington's disease storyline.¹⁵ This provoked discussion on the Huntington's Disease Association's message board after it was broadcast. One participant wrote:

Really pathetic, Doc sees someone being clumsy and that his grandfather dies early and was "mental". He told him he wanted to test him for a genetic disease. Then his brother got to know about it and demanded to know what the Dr was thinking. Dr told him Huntington's disease and took the brothers blood there and then and said he's have a result in the morning. Class, pure class

The episode led to complaints to Ofcom about the portrayal:

I was appalled when the subject of Huntington's disease (HD) was so carelessly and undiplomatically portrayed on Doc Martin. My family is being torn apart because of HD and will still be torn apart for generations because of the high hereditary factor. I was disgusted that the medical advisor in Doc Martin, who was Dr Martin Scurr, didn't even give a second thought to the affect that it could have on such families and how it was presented in such a light-hearted way for the entertainment of thousands of people. He has not done his homework has he? I would like a public apology to be given before next week's programme starts if that is possible.¹⁶

This dialogue after the broadcast of the programme illustrates the impact of these representations on viewers who are connected to Huntington's disease. The programme took various themes common to Huntington's disease discourse and dramatized them. Other medical dramas such as *House*, *Peak Practice*, and *Scrubs* have all also featured Huntington's in a similar fashion echoing perhaps the

¹⁵ *Doc Martin* Series 4 Episode 3 Television programme, ITV, (London broadcast 4 October 2009).

¹⁶ <http://hdmessaggeboard.com/>

dominant medical discourse of the past.¹⁷ The difference between those nineteenth and twentieth-century treatises and their contemporary offspring is the voice of the persons affected can now be heard. Comment at least and has been democratised and individuals empowered through such collectives as message boards and blogs.

Soap operas have often been drawn to Huntington's disease and the longer timeframe has often presented producers with a greater opportunity to explore the disease and the impact can be positive; after Huntington's disease was featured as a story line in *EastEnders*.¹⁸ The BBC press release commented on the inclusion of Huntington's in the plot, stating 'we chose to show Huntington's disease as we believe that everyone in society, no matter who, has a right to be seen', which while undoubtedly true does also contain a strong allusion to the hidden nature of the disease.¹⁹

The jeopardy of a 50-50 risk and the resulting knowledge after positive genetic testing has attracted television producers to Huntington's disease with a frequency far beyond its actual occurrence in the population and it will no doubt be a feature of drama and soap opera in the future. The interesting aspect will be the extent that the historic discourse maintains its hold on the portrayal of the illness. The evidence from recent times is that the greater openness of debate and feedback created by the internet and social media is both reflecting and leading a change in perceptions as several participants in this study have testified.

¹⁷ *House*, Television programme Channel 4 (United States 2004-2012). *Peak Practice* ITV Series 3 Episode 7 (London, broadcast 21 March 1995), *Scrubs* Series 8 episode 18 Television programme Channel 4 (United States, broadcast 2001-2010).

¹⁸ *EastEnders* Television programme, BBC1 (London, broadcast August 2004).

¹⁹ http://www.bbc.co.uk/pressoffice/pressreleases/stories/2004/08_August/14/eastenders.shtml

As diverse as cultural representations of Huntington's disease are, the themes of stigma, and the associated concealment and secrecy surrounding the disease, are clear threads running through most. Cultural representations are surely reflections of wider society's attitudes, ones in many cases informed by the dominant medical discourse of the past, which has also shown itself all too prone to reflecting the societal perceptions it helped perpetuate. Increasingly Huntington's narratives have begun to feature in print media. Stories of personal challenges with the disease and society's response to it, have often been negative representations, in which the voice of Huntington's disease sufferer remains unheard. Increasingly, however, there has been an emergence of narratives which challenge the secrecy and stigma of the past have all featured in popular print media.²⁰

Huntington's discourse is beginning to change. With this shift representations that challenge stigma are increasingly emerging. Nevertheless for many, negative or sensationalist representations will be their only knowledge of Huntington's and melodramatic, frightening or even incorrect representations can still have a far reaching impact on those with the disease and beyond.²¹ Huntington's disease representations in literature, television, and print media have increasingly supplemented the medical discourse, but also served to highlight the themes of secrecy and hiding comparable to those explored in the oral history interviews.

²⁰ For a broader theoretical overview on media and disability see Tom Shakespeare, 'Cultural Representations Of Disabled People : Dustbins for Disavowal,' L Barton & M Oliver (eds.), *Disability Studies Past Present and Future* (Leeds,1994), p. 217-233

²¹ A selection of print media representations of Huntington's disease is included in the bibliography.

Chapter Three: Oral History and Huntington's disease.

As much of the secondary literature has demonstrated, work by and for a medical audience has until recently dominated the discourse surrounding Huntington's disease; the voices of those directly affected by the disease were notably absent. It was not until work by Wexler within the last twenty years-or-so and the rise of new digital media that this medical hegemony began to be if not challenged then at least complemented by new voices. The purpose of this project is to supplement this new discourse, using oral histories to explore memories of that particular moment in Huntington's disease history when hundreds of people gathered to attend the launch of the APPG on Huntington's disease at Westminster. In addition the oral histories serve to explore the understanding of those who attended with regard to the concealment of Huntington's disease in the past, often for some by and from their closest relations.

Part One: Oral History and disability.

Using oral history provides an approach to Huntington's which was for the most part missing from the predominant medical histories of the disease and could therefore provide an appropriate method to expand knowledge by including first person experiences of the disease, its impact on individuals and families. Oral history is a valuable resource to add to or challenge dominant histories.

The launch of the APPG was covered widely in the press and on television, some voices of those attending were heard, as interviewees on television news broadcasts.¹ In addition two articles were published in *The Lancet*, one which

¹ APPG News Reports ITV : <http://www.youtube.com/watch?v=iVSjLTtUsc>
Channel 4 : <http://www.youtube.com/watch?v=iy7pOcdzqwE>

discussed the new figures about the prevalence of the disease, and another by Alice Wexler discussing the stigma historically associated with the disease.² Oral histories add additional accounts and experiences to these sources and provided the motivation for this project.

Karen Hirsch investigated the role of oral history and disability and raised issues that reflect some of the themes that have emerged previously in the medical discourse and also in the oral histories of Huntington's disease; arguing that 'people with disabilities constitute one of the most powerless groups'.³ From its beginnings oral history has been utilised as a medium to give a voice and a platform to such underrepresented groups. Hirsch believes also that 'oral history has a crucial role to play in the emergence of disability history'.⁴ Disability history is progressively exploring the direct experiences of the disabled, as Iain Hutchison, writer and researcher into disability stresses:

Like many working in the disability history field I quickly became frustrated by what institutionalised sources did not willingly tell us and my work has increasingly prioritised hearing the voices of people with disabilities above the voices of those who intervened in their lives.⁵

Issues such as models of disability, identification with a group of similarly-disabled people and cultural representations have helped present a counterpoint to the dominant medical discourse allowing new voices, experiences and ideas to emerge.

² Michael Rawlins, 'Huntington's Disease Out Of The Closet,' *The Lancet*, 376, (2010) pp.18-19.

Alice Wexler, 'Stigma. History and Huntington's disease,' *The Lancet*, 376 (2010), pp.18-19.

³ Karen Hirsch, 'Culture and Disability: The Role of Oral History,' *Oral History Review*, 22, 1 (1995), pp.1-27.

⁴ *Ibid.*, p.6.

⁵ Iain Hutchison 'What got You Into Disability History?' *Disability History Association Newsletter* Spring (2009), pp. 1-27.

Crucially Hirsch also notes that while many oral histories of disability have allowed interviewees 'to speak about their disability [...] they do not describe public events that influenced their individual lives'.⁶ By collecting oral histories from people who attended the mass lobby and launch in June 2010 of the All Party Parliamentary Group on Huntington's disease there exists the opportunity to fashion a unique understanding of what motivated people to attend and engage with what was a public and political event. In addition why they chose to speak further about the impact the disease has had and their own and their relatives lives. How the care and treatment of kin in previous generations-lives lived in conditions shaped by attitudes towards Huntington's over the centuries-came to influence the present generation can also be explored.

J. Daniel Schubert and Margaret Murphy assess the importance of oral history in contrast to medical discourse in 'The Struggle to Breathe: Living at Life Expectancy with Cystic Fibrosis', which presents insightful perspectives on life with a chronic genetic disease. Feelings, lived experiences, hopes and fears are all articulated, making oral history a powerful tool in presenting the experiences of people with a range of disabilities and disease in their own words.⁷

Oral history is a powerful tool, adding real and lived experiences to our understandings of disability and disease. New approaches and methodologies in oral history can be utilised to bring the memories, shared experiences and life stories of those with, or at risk of Huntington's disease to the growing collections of oral histories as the discipline develops and changes.

⁶ Hirsch, 'Culture and Disability: The Role of Oral History,' p. 6.

⁷ J. Daniel Schubert, and Margaret Murphy 'The Struggle to Breathe: Living at Life Expectancy with Cystic Fibrosis,' *Oral History Review*, 3, (2005), pp. 35-55.

In the past, victims of Huntington's disease have been the topic of discussion, debate and opinion between doctors, psychiatrists and geneticists; the medical view dominating the secondary literature of the disease. Seldom have the voices of those at risk of or living with Huntington's disease been heard, rarely have their stories been told in their own words. Oral histories present an opportunity to enhance emerging narratives, adding the voices of some of those who have in the past been mute.

Part Two: Design and Subjects.

This study involved two components. Firstly, oral history interviews conducted with some of those who attended the launch of the APPG, as well as some involved in the planning and organisation, and secondly, the use of questionnaires. As the theme of the APPG launch was the previously hidden aspect of Huntington's, the interviews and questionnaires were structured around this topic. The domination of medical discourse in the secondary literature and an absence of patient and relatives voices left a lack of balance in the discourse. Patient voices and experiences have been concealed, maybe for protection or ethical considerations, and this has left gaps in the histories of Huntington's disease. Oral history interviews gave an opportunity for the experiences of those who attended the event to be collected and the issues and themes raised analysed. Using the launch of the APPG on Huntington's as a case study to explore the wider issues of secrecy and stigma, add family voices and experiences to the thus far dominant medical discourse.

Oral history interviews gave participants an opportunity to both share their memories and motivation for attending the event at Westminster as well as their own experiences of Huntington's. The questionnaire similarly gathered both memories of

the event and personal experiences though in less depth than the interviews- nevertheless they were useful and enabled a broader range of participants.

The subjects selected were some of those who attended the event. They were contacted by means of social media comprising Facebook, a notice on the Huntington's Disease Association website and also included some existing contacts.⁸ However, there are limitations in this methodology as noted below and the scope of the research was constrained by time and financial considerations.

By attending the APPG launch participants had travelled to London to lobby their MPs and raise the profile of Huntington's. Many participants as stated above had also signed the banner stating Huntington's would be 'Hidden no More'. Those within the sample selected for this project therefore had already begun speaking openly about Huntington's and were prepared to participate in an oral history interview and therefore a self-selecting group of participants. However, those attending were a fraction of those people affected by the disease who did not attend the event. Whilst of course this may have been logistical - Huntington's is a disabling condition both physically and psychologically and so getting to London for many would have been impractical and expensive-nevertheless, others sometimes within the same family chose to keep the disease hidden, and therefore did not travel to London, they would be unlikely to participate in a project such as this. It is perhaps inevitably a history of those who have made most progress in casting away a secrecy that is sadly still all too prevalent.⁹

⁸ This item was put on the Huntington's disease Association website to recruit participants.
<http://hda.org.uk/news/116>

⁹ For example, this was a recent post from the HDA message board: 'My Mum had 5 siblings and many nieces/nephews only 2 tested and were negative... 2 uncles defo [sic] have it but in denial and not tested also entire rest of family in denial... so i sit alone with about 15 blood relatives who never mention the disease or ask how I am... just ignore it heads in the sand..... If I bring the subject up

Oral history as a research methodology often raises as many questions as it answers, including the reliability and nature of memory, the interview process itself and the analysis and interpretation of the data.¹⁰ Issues such as these, whilst not discussed in further detail do serve to underpin the research and the analysis. Anonymity was offered for those responding to the questionnaires, which creates ambiguity, as whilst talking about hiding the disease, the participants are still concealed. However, the lack of anonymity does raise ethical issues which will be discussed in more detail.

Part Three: Ethics.

With all research ethical considerations are of paramount importance. Research into Huntington's disease is complex as by speaking publicly about a genetic disease the risk of the disease to other relatives would be revealed, which may be against their wishes. Other threats include the potential effect of speaking openly, on friends, colleagues and employers as well as insurers. For this reason questionnaires were anonymous. For any oral history project ethical guidelines must be followed to protect the interviewees and those followed here are detailed in the Oral History Society's Ethical Guidelines.¹¹ The purpose of the interviews and possible future uses are important to any project and while these interviews were carried out as research for an MA project the research may be used for presentations to raise awareness of Huntington's disease in the future. Participants in the recorded interviews were

they just refuse to talk about it...I feel a bit like a leper!!be lovely to hear someone say "Oh i have the gene and im not ashamed"!! <http://hdmessageboard.com/showthread.php?t=4048>

¹⁰ My thinking on oral history methodologies has particularly been shaped by: Ludmilla Jordanova, *History In Practice* (London 2006), pp.54-55; Alessandro Portelli, 'What Makes Oral History Different,' in R Perks & A Thomson (eds), *The Oral History Reader* (Oxford, 2006), pp.31-42; Valerie Yow, *Recording Oral History* (London, 1994); Katherine Borland, 'That's Not What I Said' 'Interpretive Conflict in oral narrative research,' in R Perks & A Thomson (eds), *The Oral History Reader* (Oxford 2006), pp. 310-321; Paul Thomson, *The Voice of the Past* (Oxford 2000).

¹¹ <http://www.oralhistory.org.uk/ethics.php>

informed of this and all consented to participate and signed the appropriate consent forms.

Furthermore, the position of the interviewer as insider or outsider to the group or community to which the participants belong is important. This relationship can impact on the interviews and projects so needs to be carefully evaluated, as Yow explains:

The interviewer must look critically at his or her own feelings about the narrator or group of narrators, asking how these feelings have affected the questioning processes.¹²

A critical evaluation of my own position is therefore important, as a person at risk of inheriting the faulty gene and having watched several relatives die as a result of Huntington's disease, I have a relationship both with the disease and the group of narrators. As an 'insider' in the Huntington's community the questions I asked in the interviews may have been essentially different to those asked if the interviews had been conducted by an 'outsider'. Whilst I have been aware of Huntington's disease in my family for as long as I can remember and having lost my grandfather, mother and uncle to the disease when I was a child, it was not until my brother began to show symptoms that I had to confront the disease as an adult, which meant telling people both of my own risk and my genetic history. For the most part my position has enabled me to conduct interviews with some of those whose lives have been affected by Huntington's disease but have never spoken about the issues raised in the interviews. However, my position and knowledge about the disease perhaps prevented me from asking questions that someone from outside the Huntington's community may have raised. Hirsch does not see this position as problematic, but as

¹² Valerie Yow, 'Ethics and Interpersonal Relationships in Oral History Research,' *Oral History Review* (22, 1995), pp. 51-66.

an opportunity to explore a broader range of experiences dependent upon the relationship and 'different aspects of the lived experience'.¹³

Interviewees explored their own lived experiences of Huntington's disease and their memories of the APPG launch. The methodology utilised has added new voices to the existing discourse and avenues for possible investigation in the future have been illuminated. Using oral history added real voices of those directly affected by Huntington's and despite complex ethical considerations these interviews explore the themes of hiding and secrecy and more importantly possible reasons why some, have for generations, kept Huntington's disease a secret.¹⁴

¹³ Hirsch, Culture and Disability: The Role of Oral History' (22 1995)p6

¹⁴ My thinking on anonymity and inter subjectivity has been particularly shaped by Valerie Yow, *Recording Oral History* (London, 1994); Ben Jones 'Telling Family Stories: An Interpretative Authority and Inter Subjectivity in Life History Research', *The University of Sussex Journal of Contemporary History*, 7 (2004); Alistair Thomson 'Sharing Authority: Oral History and the Collaborative Process,' *Oral History Review*, 30, 1 (2003), pp. 23-26.

Chapter Four: An Oral history of Hidden No More. The launch of the All Party Parliamentary Group on Huntington's, 30 June 2010

Huntington's disease has been hidden both in history and in the present. The launch of the All Party Parliamentary Group allowed Huntington's disease families to reflect on the history of the disease and its treatment by society, with the intention to ensure that it was 'hidden no more.' These reflections and memories were captured in a series of interviews and questionnaires. The reasons participants believed Huntington's disease had been hidden were complex and will be discussed in detail. Heredity was a key theme that emerged and its impact on relationships will be explored. In addition the past treatment, of those with Huntington's disease was also viewed as an important factor in the secrecy which has surrounded the disease. However external agencies were also suggested, such as GP records, and the impact of Huntington's disease on access to financial services and employment, and social policy regarding care. Finally, memories of the day itself will be explored to evaluate how oral histories can aid our understanding of the sense that the launch of the APPG as an historic occasion in the history of Huntington's disease.

The 'Hidden No More' theme of the APPG launch with balloons, tee-shirts, badges, wristbands and a signed banner all featuring the phrase was coined by the main organiser of the event Charles Sabine. Sabine, award-winning journalist and one of those instrumental in organising the Hidden No More lobby has, since testing positive for the Huntington's gene has spoken at events around the world to raise awareness and improve the lives of those with and at risk of Huntington's disease. In an interview in the *Guardian* he said:

I chose to come out of the Huntington's closet, so to speak, in 2007 because I wanted to make a difference. Huntington's patients suffer in silence. There is a

lot of shame surrounding the disease because patients appear to be out of control' thousands of people in Britain are hidden away as a result.¹

When starting to plan the APPG launch he recalled, 'I kept thinking we needed a title and kept seeing the letters HD and thinking how we could put hide or hidden[...] I did a sketch Capital H i capital D den HiDden No More and realised that was exactly what we needed and it worked with the letters.'²

Charles Sabine has tested positive for the Huntington's gene and as well as being instrumental in setting up the APPG, he also works as an advocate for those affected directly or indirectly by Huntington's disease all over the world. He sees the concealment of Huntington's as one of the biggest problems facing those affected by the disease and points out that:

it is apparent to me that the disease was hidden it had been hidden in my family. Almost every single family, almost without exception not just in the UK but around the world had stories about how Huntington's disease had been hidden in their family or how it was still hidden.³

This culture of secrecy and surrounding stigma and shame, Sabine believes, is one of the major problems still facing Huntington's disease families:

it has become abundantly clear that perhaps the single biggest problem, though many difficulties and problems face the Huntington's disease community is by far the stigma and shame surrounding the disease.⁴

Most participants agreed that Huntington's disease had been hidden in the past and some clear themes arose from their experiences as to why this was the case. The

¹ Susan McClelland, 'I will die the most horrible death', *The Guardian*, (11 August 2009).

² Oral history with Charles Sabine, 23 February 2013. Conducted by the author. Charles Sabine has been tested positive for the Huntington's disease gene. His father and uncle died from the disease, he has a brother who is symptomatic. He is an advocate for the Huntington's disease community and speaks at events and conferences all over the world. He was instrumental in setting up the APPG.

³ *Ibid*

⁴ *Ibid*

themes which emerged from the interviews and questionnaires encompass all those issues of stigma and concealment evident in much of the historical discourse and many of the cultural representations.

Part One: Heredity

For most families an heirloom from generations in the distant past may be a set of silver spoons, a piece of jewellery or perhaps a dinner service. For those in a family affected by Huntington's disease the heirloom is silent and invisible yet devastating in its destruction. The genetic transmission and hereditary nature of Huntington's disease was discussed by interviewees and those responding to the questionnaire as one of the reasons they felt many had hidden the disease. The concealment was often combined with guilt felt about passing the gene onto children and future generations.

The disease's genetic impact and heredity was deemed by many participants a contributory factor to the secrecy and concealment both within kin and beyond. For those who attended the launch of the APPG on Huntington's their own experiences and feelings about the importance of heredity on concealment can be recorded and added to those histories collected by the medical observers in the past.

The impact of heredity was considered by Mary who gave an account of how the marital breakup of her sister's marriage led to the revelation that her sister's husband came from a family affected by Huntington's disease. A chance meeting with someone when out shopping who 'mentioned the words Huntington's disease' sent her sister dashing to the library:

She rang me up and she told me because I was a nurse. I looked it up in my medical book and there was about four lines on it. I went to the doctor and he explained it was very rare, but of course hereditary, a factor which hung over us for years.⁵

She explains how the Huntington's had been concealed:

'Well I mean from our experience obviously it was hidden from the very beginning there must have been some people in the family that knew about it , it has always been regarded as a secret disease people didn't want to talk about it'.⁶

Mary also considered important the genetic nature and 50 per cent risk of every child born to an affected parent. She spoke about how the knowledge of the risk to children born to a parent with the disease in some cases added to the layers of secrecy and how this silence could have potentially exacerbated feelings of shame and guilt:

anything that is hidden has a guilt thing about it as well. I think mainly because of the hereditary factor that is a big, big thing to cope with within a family, so whoever it is, the mum or dad, your children are the most precious thing in your life and to think something that's within your side of the family can be passed on. That's a big burden.⁷

Sarah also recalled her experience, when they learned that her grandfather had died from Huntington's and how the genetic transmission would impact on her father and his siblings, all of whom bar one would go on to develop the disease.

When my granddad died the doctors called my dad, who was the eldest son, into the hospital and told him that his father had Huntington's, which was a genetic disease and hereditary. They gave him a leaflet saying it was the worst illness known to doctors. Immediately there is a massive fear created because if you are told that it is the worst illness known to doctors and the disease of the

⁵ Oral History interview with Mary Howlett, 4 April 2013, conducted by author. Mary, 70, is a member of the Merseyside branch of the Huntington's disease association. Several members of her sister's family have been affected by Huntington's disease.

⁶ *Ibid*

⁷ *Ibid*

devil and that kind of thing you are not going to start talking to other people about it.⁸

An inability to communicate the risk of inheritance to offspring and fear of the impact that risk of inheriting the faulty gene may have on many facets of life is also considered by some participants. A respondent to the questionnaire (Participant 1) explained how this had perpetuated the secrecy in her own family and affected the relationship with her husband, who has Huntington's.

One of the things he says he's most cross about is that his parent's didn't tell him until he was about 23 even though they'd known for twenty years. He felt he had a right to know about his possible future – however, he now refuses to let anyone know including the kids (Participant 1).⁹

A difficulty in communicating the consequences of Huntington's to others who may be at risk and lack of knowledge to deliver such information is also something Sarah experienced.

For my mum to talk with me and my brother about it because of the implications it always tended to be hidden and not talked about and the same with my surviving uncle they didn't have the skills or experience to talk about it within the family because it was such a horrible thing and people are so frightened of it.

Dr Ed Wild also highlighted heredity as one of the prevailing features of Huntington's which has caused it to be hidden in many families. He works as a clinician lecturer

⁸ Oral history with Sarah Appleby, 12 April 2013, conducted by author. Sarah is 48 and at risk for Huntington's. Her brother is in a nursing home and her father and two uncles died from complications of Huntington's disease. Other family members are at risk.

⁹ Questionnaires were anonymous and have been numbered Participant 1, 2 etc. Participant 1, Female, 21-35, the wife of a Husband with Huntington's disease and children at risk.

and researcher into Huntington's and also edits the HD Buzz, a website which collates research news from around the world.¹⁰ Wild observed,

It is a disease which is inherited and so the children of people who have the disease are at risk of inheriting the disease themselves. What that means is whole families can end up being labelled as people who have a disease which causes symptoms that may be embarrassing or awkward for other people to deal with. Obviously there are considerations around marriage and partnerships and the choice of having children or not, so for many years there was an almost tradition of stigma or shame which developed around Huntington's disease where families wouldn't talk about it, because if it was kept hidden then that would be the best chance the kids at risk would have of being able to have a normal life getting married ,having kids and of course 50 percent of those kids wouldn't get Huntington's so that strategy sort of paid off in a way.¹¹

Heredity and its associated stigma and guilt have contributed to the concealment of Huntington's disease. Relationships, marriages and reproduction options are all compromised and the associated guilt, fear and isolation led many to hide the disease from the others both inside and outside the household. The inheritance pattern that attracted Huntington's disease to medical observers in the past is significant in the concealment of the disease, often for generations, and is what still sets it apart from many other diseases. Yet heredity is not the sole reason Huntington's disease had been hidden and the treatment of those with Huntington's in the past was also an important theme raised by participants in the interviews and in replies to the questionnaire. .

Part Two: Family secrets

Dynamics vary from one family to another and secrecy concerning Huntington's disease within them and beyond was a recurring theme which emerged from the

¹⁰ En.hdbuzz.net Huntington's disease research news. In plain language. Written by scientists. For the global Huntington's disease community

¹¹ Oral history interview with Dr Ed Wild, 23 February 2013, conducted by author. Dr Ed Wild is a Clinical lecturer in Huntington's disease and founding editor of the HDBuzz website.

interviews. As symptoms become more obvious in an aunt, uncle, brother or sister or a genetic test confirms the disease, it often becomes more difficult to conceal. Yet openness about the disease is also a complex position for many with advantages and drawbacks, often in flux causing tensions and even cracks within relations. The resulting isolation and fractures between relations caused by this conflict was commented on by several participants, as Mary reflected 'It has always been regarded as a secret disease, people didn't want to talk about it. It broke up families.'¹²

Though many participants agreed that a shift towards awareness and openness to be the best way forward this approach is not without problems and can cause pressures within families, as Sabine explained:

For me to be open about it means my family effectively has to be open about it and they weren't all of the same view as me[...]one of the problems with Huntington's disease is that you take your family with you. It hasn't caused any problems with my immediate family i.e. my brothers children although I know they would rather I hadn't been so open we do still talk.¹³

In addition, being more open about the disease does not just impact on immediate members. For Sabine it also had consequences in the extended family that had been keener to keep Huntington's hidden.

There's a whole other side to my family connected to my uncle who are absolutely apoplectic with what I have done and think it completely wrong. They know people on their side of the family who are at risk and they don't believe they should find out¹⁴

¹² Oral history interview with Mary Howlett.

¹³ Oral history interview with Charles Sabine.

¹⁴ Ibid.

While most people are not as high profile as Charles Sabine, his experience demonstrates the wider implications of not hiding the disease. A gene positive relation effectively reveals the rest of that family's risk. Charles' experience vividly illustrates the conflict of both of hiding and revealing Huntington's disease.

Breakdown in close relationships was also discussed by other participants, as some members either hid from those affected or hid their existence from others. Tony recalls the treatment of his wife, who has Huntington's and is now in a care home, by her mother and sister. 'Her mother was sort of Victorian, even saying "what have you done to bring this awful disease on the family?"'¹⁵ He remembers how she seldom visited her daughter and speaks about the estrangement of his wife's sister: 'She is in absolute total denial and never phones, never comes to see her, her mother died two and half years ago and that was the last time we saw her'.¹⁶ Tony and his wife were invited to a family event but were told that their presence would be problematic. Tony recounts his brother in law's explanation:

I haven't told her. (that Tony and his wife were invited) because she'll explode, I don't know why. I keep trying to say come on we'll have to visit your sister and we have the most awful marital rows which we have never been used to I don't know what is at the bottom of it.¹⁷

The strain of keeping the disease hidden or speaking openly about the disease in families and the impact it has on many relationships is clear. The difficulties were also explored by other participants; the gamut of emotions is described by

¹⁵ Oral history interview with Tony Wardell, 25 March 2013, conducted by the author. Tony cared for his wife who has Huntington's until she was moved to a care home. He has children at risk. Tony is the chair of the Nottinghamshire Branch of the HDA.

¹⁶ *Ibid*

¹⁷ *Ibid*

Participant 2 who considered the difficulties that both openness and secrecy can bring

I think the effects of concealment can be devastating. I have two sisters, one of whom, thankfully does not have the gene. The other sister is reluctant to discuss the illness. Both sisters have children none of whom really know about Huntington's disease. I worry that my untested sisters children are growing up in an environment where they know nothing of Huntington's, yet they might have to deal with their mother having the illness and themselves being at risk[...]yet I too am guilty of it as I struggle deeply with the prospect of my nieces and nephews becoming aware of my health status[...]I know children can deal with difficult health issues far better than adults, so it probably due to my own fear or reluctance to face up to the illness.¹⁸

The issues of trust that secrecy brings were also highlighted by Participant 8:

I think that if Huntington's disease is hidden from members of a family it can cause trust issues and questions. My cousins were not told about it, so it was difficult for me because they are also 50-50 like me. They asked me why they weren't told but considering they're older than me I couldn't answer.¹⁹

The impact of Huntington's disease on families is a clear theme running through the responses and the reasons for these fissures in familial relationships are often as complex as the disease itself.

Participant 4 describes her experience after the death of her husband from Huntington's disease.

'When [he] died, his sister came to the house, she said she had mentioned to her colleagues at work who assumed her younger brother had died when they heard she had lost a brother. She had never told them about having another brother. It was as if she was ashamed to have a brother with Huntington's disease yet I have to take on board by discussing her older brother and his death she would be giving her colleagues potential information about her own health status'²⁰

¹⁸ Participant 2: Female, 21-35, has tested positive for the gene and has other family at risk.

¹⁹ Participant: 3 Female, under 21, is at risk of the disease and has other family members with the disease and at risk.

²⁰ Participant 4: Female, 36-50, cared for her husband with Huntington's until his death two years ago.

The increasing challenge of the physical and psychological symptoms of Huntington's disease and the lack of any effective medical treatment added to the secrecy surrounding those affected. Increasingly, for some, it led to the disease and those suffering being hidden both literally in lunatic asylums and metaphorically too, as for many the disease was not named or spoken about or if it was it was in hushed tones.

Sarah recalls the attitude towards Huntington's, growing up in the 1970s:

Even in our family nobody really ever said the word Huntington's. People might whisper 'the illness' but that was as far as it went. There was no real discussion about Huntington's at all in our family only if it was really necessary when it was clear a family member was suffering, but again it was always called the illness.²¹

Treatment and confinement in asylums was a subject raised by interviewees when talking about the hiding of Huntington's disease and probable reasons for it.

The literal nature of the concealment of Huntington's patients in asylums has hardened families' reluctance to speak about the disease. Charles Sabine emphasised this:

Why would anyone admit to having a disease when a generation ago the likely response of society would be to put them in a padded cell and feed them through a hatch, who'd want to admit to that? No one of course, It is not surprising people hid the disease.²²

Charles recalls how an uncle he never saw and knew little about was secreted away out of sight in a home. However, hiding away became less of an option when his

²¹ Oral history interview with Sarah Appleby.

²² Oral history interview with Charles Sabine.

father had the genetic test in 1994. This secrecy and its effect he believes goes back generations with many sharing similar experiences. He reflected on his own realisation that his own parents knew about the existence of Huntington's disease for years, but it was not discussed:

My uncle was in an HD care home already and I had never seen him, never seen a photo, never met him because he was hidden away he was just referred to as the black sheep. They would have carried on like that had it not been for the fact that my father became one of the first people to take the genetic test in 1994 so they couldn't hide it any more it was in black and white.²³

The stigma of having a parent, grandparent, aunt, uncle, sibling or child in the lunatic asylum and the knowledge of the hereditary transmission of the disease meant that it was unlikely that they would be the only one affected, which led to further secrecy and silence. Those like Charles's uncle were exorcised from family histories. Given the incentives to conceal Huntington's disease, there is evidence that in some cases unspecified mental and psychiatric disorders were noted on records rather than Huntington's, as Mary remembered how her brother-in-law's mother was:

in a psychiatric hospital but the story we had been told was that the poor lady had had a breakdown after the birth of her fourth son, and it was sort of feasible but it turned out three of the boys out of the four had Huntington's.²⁴

Whilst treatment and care for those with Huntington's disease is now changing, for many the last months of their lives will still be spent in specialist care; these care homes seem lighter and brighter than the gothic institutions of the past. The memories, perhaps fading, but deeply resonant nonetheless, of those mothers, fathers, uncles, aunts, brother, sisters and grandparents locked away in the asylum

²³ Oral history interview with Charles Sabine.

²⁴ Oral history interview with Mary Howlett.

may well still be contributing to the culture of silence which has surrounded Huntington's for some. A culture of silence, of secrecy, of shame may well have passed through generations transmitted as mutely as the gene itself and while some will develop the disease and others escape the reverberations leave all members touched in one way or another.

Part Three: Huntington's disease and society.

Whilst Huntington's disease by its genetic nature is a familial disease the position of those affected and their treatment by society were also considered by participants as contributory factors in the concealment of Huntington's disease. This wider context should not be ignored and the fears, reactions and often ignorance of wider society now becomes the focus of analysis.

A lack of awareness or knowledge about the disease by the wider public was viewed as a reason for the concealment of the disease with the consequence often being a vicious circle of decreasing knowledge and awareness. Huntington's disease and the slow degenerative progression gradually take the person from the 'ordinary'; someone with a career, hobbies and interests, hopes and dreams, to someone exhibiting strange behaviour, unusual movements and inability to complete even the most basic tasks. These behaviours can cause embarrassment and even fear both to relatives and other members in society, making it easier for some with the disease to shy away from society, rather than challenging negative reactions and real or

perceived prejudices.²⁵ Participant 5 suggested the gathering at Westminster that day challenged this attitude in an organised and public way:

HD has been a disease that is not socially acceptable as some of the symptoms are 'embarrassing' to normal society. This is changing with greater awareness and the APPG initiative is a huge step forward in normalising the disease and making it acceptable – genuinely Hidden no More[...]it's not been directly hidden but is a relatively rare disease compared to something like Alzheimer's meaning less people will be aware of it. That and some of the socially unacceptable traits of the disease meant it has to some extent been swept under the carpet.²⁶

By 'normalising' the disease it might be possible to eradicate the stigma that is attached to it. Fear of the unknown was emphasised by Participant 6:

Families sometimes try to hide it because of prejudices in society [...] as people are not aware of Huntington's disease and are frightened of the unknown.²⁷

By attending the launch of the APPG many participants felt prejudices might be challenged and awareness raised.

However, many had experienced the lack of awareness and knowledge in wider society and the impact of this did reoccur in many participants' responses. Matt talked about his experiences:

It's just very unknown by the general public, if they have heard of Huntington's they don't really know what it is and you often find yourself comparing it to Parkinson's disease just so people will have a kind of idea what Huntington's disease is. It is a really big struggle to make people aware there is that stigma there you feel isolated you are the only one going through this and no one really understands so that kind of stigma is around.²⁸

²⁵ Neil Sears, 'Restaurant bans disabled artist for putting off diners,' *The Mail Online* (12 July 2008).

²⁶ Participant 5: Male 36-50, who has tested positive for the gene and has a daughter at risk

²⁷ Participant 6: Female over 50, who has tested positive for the gene. She has siblings with the disease and children at risk.

²⁸ Oral history interview with Mathew Ellison, 23 February 2013, conducted by the author. Matt is 23 and has tested positive for the gene, he has family members at risk and gene positive. He is a founder member of the Huntington's disease Youth association HDYO.

The range of symptoms including jerky movements, the difficulty in speaking, eating and sometimes challenging behaviours can make someone with Huntington's appear drunk or out of control and could be seen as anti-social if one had no knowledge or experience of the disease. Sarah assessed the impact on wider society:

It ends up being hidden because of the shame of having an illness that causes such difficult behavioural problems to the wider community, so it tends to be hidden. I imagine it also hidden because of the stigma attached to it.²⁹

Heth Dagger viewed the awareness generated that day as a positive counterpoint to the treatment of people with Huntington's' disease in the past:

'It doesn't need to be hidden away instead of people going straight into mental asylums and things like that in the past where it was really misunderstood and the whole family were shunned.'³⁰

She saw the openness and awareness the APPG launch generated as a positive for those with the disease and upon the reactions of wider society to them:

it was out there in the open and for that day. There was the media as well, so you got the internet, radio TV, while it doesn't necessarily become a household name it did become something people were more familiar. People are quite afraid[...]it does look quite scary when you've got someone flailing down the streets with wild movements that can't speak properly and you have no understanding of that then it is going to be scary, but once you have that information you can do something about it.³¹

Surprisingly no participants spoke or wrote about the assumption often made by the wider public and even those in authority such as the police, that a person with movements of chorea caused by Huntington's is drunk. It may have been the design of the questions or a lack of probing in interviews that meant this experience was not

²⁹ Oral history interview with Sarah Appleby.

³⁰ Oral history interview with Heth Dagger, 6 March 2013, conducted by the author. Heth is 36 her mum Jill has Huntington's disease. Heth has tested negative but has other family members at risk.

³¹ Oral history interview with Heth Dagger.

raised, though it has been covered in the analysis of cultural representations as it was a factor mentioned in many of the news media articles about Huntington's disease.³² Notwithstanding this omission, both the perceived and actual responses of society at large to those with Huntington's disease has undoubtedly contributed to the concealment of the disease and the stigma which has surrounded it.

Part Four: Prevalence figures.

Genetics, symptoms and treatment of those with the disease have contributed to its concealment. However, further avenues for analysis were highlighted by participants. Misdiagnosis, or in some instances deliberate concealment by GPs and the impact of this on prevalence figures, was an important focus for the APPG launch. Several participants in this research have mentioned misdiagnosis by GP's which may have contributed to the anomalies in prevalence studies or deliberate concealment of Huntington's both within families and on death certificates. Ed Wild cites this as one of the primary reasons Huntington's disease has been hidden:

Huntington's disease turns out to be twice as common as we previously thought [...] and partly it's to do with science and statistics there are ways of collecting data about disease s that are relatively rare that are not very effective and they end up producing under estimates and we rely on things like death certificates and GP records that are not reliable or comprehensive.³³

This lack of reliability by either ineffective data or apparent concealment by GPs is also highlighted in participant's responses to the questionnaire. Participant 5, for example, recalled how her husband's mother enlisted the GPs help to conceal the

³² Jaya Narain, 'Woman With brain disorder arrested and locked up because police thought she was drunk,' *The Mail Online*, (26 May 2008).

³³ Oral history interview with Ed Wild.

disease, an attitude with she believes led to the 'culture of denial' in her husband's family. After the diagnosis of Huntington's in his father she recalls how 'once confirmed the children were told but the mother would not allow the children to talk about it. She even went her husband's GP and forbade him to mention Huntington's disease again when he spoke to him about a routine test for something else'.³⁴

Participant 4 stated that 'I have personal experience of a doctor telling staff that the family must not know!' and Participant 7 said 'HD is not mentioned specifically on death certificates'.³⁵

Charles Sabine also shared this experience and observed how this affects the prevalence figures and has a knock on effect on social policy with regards to research and care and important focus for the All Party Parliamentary Group:

One thing pointed out in prevalence research statistics set up by the APPG is the underestimation by GPs. Deliberately knowing that a family have HD they have not put HD on record as they want to protect family from any future problems[...] the research also discovered Huntington's disease was often not mentioned on death certificates [...] Huntington's disease was not written on his death certificate, he did die because of Huntington's it he had pneumonia which is strictly speaking what killed him.³⁶

The difficulty in accurate diagnosis may also contribute to the 'hiding' of Huntington's disease. With many of the symptoms of Huntington's disease being similar to other neurological or psychological conditions an accurate diagnosis can sometimes be painstakingly slow, as Tony recalls when his wife began experience difficulties including a series of 'unexplained car accidents' After one such accident they visited the GP. He remembers:

³⁴ Participant 4; Participant 7: Male over 50, tested negative for the Huntington's gene with several family members at risk of suffering from the disease.

³⁵ Participant 4 & Participant 5.

³⁶ Oral history interview with Charles Sabine.

They didn't really dismiss it but they said we don't really know what it is yet. When we were referred to consultants and that went on for about two years. Even after an appointment with the Huntington's disease specialist for the area a diagnosis of Huntington's disease was still not confirmed he told us there is a neurological condition but I can tell you it is not Huntington's I have seen hundreds of cases³⁷

An appointment with another neurologist proved inconclusive, but after further tests, and two more years a diagnosis of Huntington's disease was made. Of course, for some, those with Huntington's have died before any symptoms have manifested or they were never diagnosed with Huntington's adding another layer of difficulty when symptoms appear in their offspring like Tony's father in law who died at 71. He remembers, 'he never really showed any classic signs except he was clumsy' Jill also shared a similar experience:

Mum had it from her dad but he had died just before she was born, mum hadn't spoken about Huntington's before we didn't know that was what mum had, it was only after tests following a stroke that Huntington's was mentioned.³⁸

The difficulties in accurate diagnosis and inaccurate details on death certificates has contributed to prevalence figures for those with Huntington's being underestimated.

Having discussed some of the reason why participants felt Huntington's disease has been hidden and the impact on generations including issues of trust, isolation and estrangement, the hiding of the disease has also had a more far reaching impact on social policies such as funding for care, treatment and research.

³⁷ Oral history interview with Tony Wardell.

³⁸ Oral history interview with Jill Bradley, 6 March 2013, conducted by author. Jill has Huntington's disease. She has other family members who are at risk. Her daughter Heth has tested negative.

Professor Sir Michael Rawlins' paper in the *Lancet* was published to coincide with the APPG launch. It highlighted the discrepancy between actual and reported figures of those affected by and at risk of Huntington's disease; discrepancies partially caused by the hiding of Huntington's disease discussed thus far. The impact of these figures was addressed in the House of Commons in the session the day after the APPG launch:

Mr Mark Williams (Ceredigion) (LD): The Deputy Leader of the House is aware of the impressive lobby of this place yesterday by the Huntington's disease Association. Will he give us time for a debate to consider the challenges facing the 6,700 people diagnosed with Huntington's disease, particularly those to do with accessing insurance and the adequacy of research into a hitherto incurable disease?

Mr Heath: I am grateful to my hon. Friend for that question. I, too, yesterday met constituents who either had Huntington's disease or who were caring for people with Huntington's disease. It brought home to all Members of the House who had contact with those people how difficult the disease is to manage. It is a degenerative disease with a genetic component that imposes a great deal of stress both on those who contract it and those who care for them. I know that there are clear issues about future research and the sort of support that can be given at the point of diagnosis and the point of management in GP practices and elsewhere in order to help. I understand that an all-party parliamentary group on Huntington's disease has been established and that is a welcome step forward. I cannot promise my hon. Friend a debate in the next two weeks, I am afraid, but he might care to apply for an Adjournment debate or a Westminster Hall debate on this important subject'.³⁹

The most recent prevalence study confirmed that prevalence had been widely underestimated and the higher prevalence figure will provide both challenges and opportunities for the help support of those with Huntington's disease.

The prevalence of diagnosed HD is clearly substantially higher in the UK than suggested from previous studies. By extrapolation to the UK as a whole, it is estimated that there are more than 5700 people, aged 21 years or more, with HD. There has also been a surprising doubling of the HD population between

³⁹ <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm100701/debtext/100701-0005.htm>

1990 and 2010. Many factors may have caused this increase, including more accurate diagnoses, better and more available therapies and an improved life expectancy, even with HD. There also appears to be a greater willingness to register a diagnosis of HD in patients' electronic medical records. Such a high prevalence of HD requires more ingenuity and responsiveness in its care. How to appropriately care for, and respond to, so many individuals and families coping with the exigencies of HD demands our greatest resolve and imagination.⁴⁰

Clearly more accurate reporting of Huntington's disease is occurring and the prevalence figures are reflecting this. These statistics may also indicate how those affected by Huntington's or at risk are becoming more open about the disease in an increasing culture where Huntington's disease and those with it are moving out of the shadows.

Part five: Modern life.

Employment worries and financial concerns were reasons given for keeping the knowledge of risk or a positive gene test secret. Reactions of employers and the difficulties accessing financial services such as insurance were raised by participants. Having parliamentary representation in the form of the APPG would, it was hoped, further legislate for employment and financial rights. However, the insurance penalties for those with a genetic history are real and add to the stigma surrounding the disease.

On the same day as the All Party Parliamentary group on Huntington's disease launched, the *Guardian* published an article exploring the insurance penalties.⁴¹ It

⁴⁰ Stephen JW Evans, Ian Douglas, Michael D Rawlins, Nancy S Wexler, Sarah J Tabrizi, Liam Smeeth, 'Prevalence of adult Huntington's disease in the UK based on diagnoses recorded in general practice records,' *Journal of Neurology, Neurosurgery and Psychiatry*, 84, 10, (2013), pp. 1156-1160.

⁴¹ Sarah Boseley, 'Fear of insurance penalties keep Huntington's sufferers in the shadows,' *The Guardian*, (30 June 2010).

explained that 'Huntington's disease is so genetically predictable that insurance companies make it an exception to the general principle of not penalising people on the basis of their genetic makeup.' Moreover, it is the only 'genetic condition for which the insurance industry loads those as risk.'⁴²

Sabine also highlighted this as a contributory factor to people's concealment of the disease:

Not surprisingly people hid the disease, people to this day are concerned about working rights, health insurance mortgages and this compounds the issue and gives people a reason to hide the disease [...] one reason prevalence figures are underestimated is GPs deliberately knowing that a family have Huntington's disease have not put Huntington's on the records as they want to protect family from any future problems they may have getting insurance or having problems with an employer⁴³

Sarah also expressed the opinion, that, while on the whole she believes that in order to get better access to research and health care, it is better 'to be in the open'; she acknowledged the difficulties for individuals and understand why people have continued to hide:

If you are, like a young relative of mine starting out on life at risk then you don't want everyone to know that your future could be tainted by that in terms of education, employment, future relationships.⁴⁴

Even broaching the subject of risk, positive genetic test, diagnosis or symptoms with employers has not always generated the support that perhaps might have been expected in a place of work. Participant 2 wrote that in addition to the stigma surrounding the disease there is also:

⁴² *Ibid*

⁴³ Oral history interview with Charles Sabine.

⁴⁴ Oral history with Sarah Appleby.

A fear that families will be excluded from crucial social activities e.g. employment and financial services. I know a huge factor in my facing up to the illness was a the fear of the effects on these areas[...]after much anguish I told my employer about the illness and explained that I would like to share my position as part of fund raising/awareness raising . My employer has been supportive however interestingly, I was told although I could raise funds, I should not directly reveal how I am affected as it would be too upsetting for colleagues.⁴⁵

While access to insurance is a fairly recent problem, employment and the inevitable loss of work as the disease progresses has been common to many with Huntington's disease, past and present. For many, onset of the disease would strike at the prime of most peoples working lives and a disclosure of this risk could put potential employers off. Participant 5 had not disclosed his Huntington's status to employers or colleagues 'I never breathed a word of my HD status to those I worked with in my previous job [...] probably wouldn't have made any difference but I wouldn't take the chance'.⁴⁶ Even being open at work poses potential problems, with colleagues and employers and once again presents another reason many have kept Huntington's disease hidden.

Part Six: Policy and Huntington's disease.

The significance of attending the launch of the APPG at the heart of government, the place where decisions central to their lives were made, stood out clearly in many participants' responses. Their hopes rested on the potential magnitude that being 'Hidden No More' could have on social policy with regards to care, support and

⁴⁵ Participant 2.

⁴⁶ Participant 5.

research. While overriding memories of the event were positive some participants did express a sense of disappointment that the initial hope and excitement that was created does not appear to have been converted into actions-or if progress has been made as a result of the APPG on Huntington's, then it is not being communicated.

Access to care for those with Huntington's disease and its quality, was a vital concern to some participants and while attending the APPG at Westminster and lobbying their MPs was for some the first time they had engaged in a political act. Others had engaged in the political process previously regarding care and support for affected relatives. Both Sarah and Mary had written to their MPs on this matter. Mary said that she had written to her MP 'mainly about respite care' and Sarah recalls how she 'had never done anything political before I had never been interested in anything though once I had written to my MP about my brothers continuing care'.⁴⁷ With a change in the financial climate, Sarah was also concerned about future care: 'I felt positive until the recession and now with all the cuts in funding for care I feel very disillusioned'.⁴⁸

The importance of solidarity the meaning of standing together outside the Houses of Parliament and a profound sense of pride was conveyed by all participants, in addition to the expectation that those who make the decisions were taking notice of this very public step out of the darkness for Huntington's disease families. Sarah recognised this:

We felt for the first time someone was taking notice of Huntington's disease families and felt very proud to be walking outside the Houses of Parliament. It was important because Westminster is at the centre of power[...]just to stand

⁴⁷ Oral History interviews with Mary Howlett and Sarah Appleby.

⁴⁸ Oral history interview with Sarah Appleby.

outside and have senior politicians recognising Huntington's and to have the media interest was such a positive experience.⁴⁹

The significance of gathering at Westminster was important to both Heth and Tony and surpassed any direct political action, though many who attended did lobby their own MPs.

I didn't really know about the politics but I did recognise the importance of being at the heart of government. It made it bit more monumental the fact you are there in the middle of where all the decisions are made and where things are passed or not passed.⁵⁰

Cath Stanley recognised the prestige of the location:

it was important it was in Westminster, it was really important as actually that is where decisions are made about health and social care and it was really important it was in the hub of that.⁵¹

As someone who worked closely with the organising committee as well as patients in his clinical capacity, Ed Wild summed up what he saw as an acknowledgement of the responsibility both of those attending the APPG and of government and society:

I think we have now reached the stage where from every direction honesty is our best weapon against Huntington's disease and people from Huntington's disease families and the people who look after them including professionals need to be open and honest [...] a community being comfortable with itself and at the same time demanding that society be comfortable with it and treat it equally [...] these were British tax payers saying there are this many of us and we have previously been hidden.⁵²

⁴⁹ Oral history interview with Sarah Appleby.

⁵⁰ Oral history with Heth Dagger.

⁵¹ Oral History interview with Cath Stanley, Cath Stanley is the Chief Executive Office of the Huntington's Disease Association.

⁵² Oral history interview with Ed Wild.

He reflected on how this concealment had impacted on funding for care, research and treatments but was adamant this should not go on unchallenged:

This is a thing that is here whether we admit it or not and the first side of curing a problem is acknowledging its existence and the flip side of that coin is you're not allowed to pretend we don't exist anymore[...]stigma has made it appear there are half as many of us than there actually are but that is not something we are going to stand for any more, we require for it to be acknowledged there are this many of us and not giving us the care and assistance we need is no longer an option.⁵³

Whilst the launch of the APPG was not the sole catalyst for a movement out of the shadows for those affected by Huntington's it did come at a time when the zeitgeist was changing and the impetus towards secrecy was beginning to be eroded. The rise of social media and message boards, breakthroughs in research that might lead to clinical trials and specialist websites such as HDBuzz and Huntington's disease Youth Organisation has led to a more open discussion about Huntington's disease as well as easier access to information. Ed Wild sees this as an indirect yet important impact of the APPG:

I don't think it is a coincidence that shortly after that young people from HD families in the UK started to get together with young people from other countries leading to the Huntington's Disease Youth Organisation (HDYO) [...] it's a truly monumental statement by a generation of young people to say what the APPG said which is this disease isn't going away but we will stand together and fight it.

Financial support and access to care or respite services, funding for research and drug treatments all require money and resources. The launch of the APPG and a

⁵³ *Ibid*

recognition of Huntington's disease in parliament will be important for the future of those affected by the disease.

Chapter Five: Memories of the day. Green Balloons and sunshine

The 30 June 2010 was an historic day in the history of Huntington's disease with the launch of the APPG, Huntington's disease would be represented in Parliament and those suffering with the disease their kin and carers given a voice. As television and radio ran stories about Huntington's disease, hundreds of those whose lives had been affected by Huntington's for generations made their way to London and the heart of government. It was a moment in time where those affected by Huntington's disease, so often concealed in the shadows of families and histories, stepped out into the sparkling June sunshine. By using oral history the importance of the day to those who travelled to London has been recorded. Using their own words some of those who were part of this significant day have added their voices to record of that day in June.

As most of those affected by Huntington's will face disability, Hirsch's exploration of the increasing use of oral history as a tool of expression for disabled individuals and groups and how this is contextualised in the wider field of disability history is valuable. She does, however, identify some limitations, as at times people;

are speaking about their disability experience, they do not relate their stories to places or time periods and they do not describe public events that influence their individual lives the presence of a disability in each individual's life story is not sufficient to create a sense of a group with shared experiences.⁵⁴

⁵⁴ Hirsch, 'Culture and Disability, 'The Role of Oral History', p.16.

Many of those who travelled to London were disabled by Huntington's, others carry the gene or live at risk. They went to share in a very public event and in an open letter. Charles Sabine addressed those who attended an important and critical day in Huntington's disease history:

All those families who came from every corner to make people take notice I will say it again; without you this even would have been a weak feeble shadow of the momentous day it became. You should feel very, very proud to have been part of such a moment in history. I certainly am.⁵⁵

This sense of history and immense pride as well as an appreciation of shared experiences was expressed. Participant 8 travelled with her husband and children and summed up her memories of the day:

a sense of community, belonging, hopefulness for the future. I was proud to be part of a breakthrough moment in history. For the first time I no longer felt alone surrounded by others who understood.⁵⁶

Others shared this feeling of fellowship Participant 9 'felt part of a big family'.⁵⁷

Participant 10 stressed the importance of a 'wonderful meeting of persons involved with their families and those who strive to find a cure'.⁵⁸ Jill shared these positive memories:

⁵⁵ Charles Sabine, 'APPG on HD Open Letter of Thanks Charles Sabine,' <http://hda.org.uk/news/67>

⁵⁶ Participant 8, Female 21-35, has tested negative for the gene but lost her mother recently to Huntington's disease.

⁵⁷ Participant 9, male over 50, cared for his wife until she went into residential care.

⁵⁸ Participant 10 Female over 50, has tested negative but has a sister with Huntington's and other family members at risk

It seemed like we were doing something special. Although I didn't meet everyone it was just nice to be with other people in the same situation because you know what they are struggling with

Tony shared these feelings: 'I was just overwhelmed, the support for the event the number of families that were there'.⁵⁹ These responses, suggest that as well as standing up as individuals, those attending did feel as though they shared an identity with a larger 'Huntington's family.'

In addition to meeting others affected by Huntington's disease, the speakers who attended also played an important role in the event and the memory of it for participants. As well as politicians and clinicians, speakers also included Nancy and Alice Wexler, news reader Martyn Lewis, singer Tony Hadley and organiser Charles Sabine. The involvement of high-profile supporters was powerful and the opportunity to speak with them significant particularly as many of them are personally affected by Huntington's disease themselves.

Participant 8 was inspired to meet 'Nancy Wexler, Charles Sabine and Tony Hadley'.⁶⁰ Tony Wardell remembered meeting Nancy Wexler and recalls the impact 'Nancy Wexler turned up. She is the professor who isolated the gene in South America in the 1990s she gave a talk and I went to speak to her'.⁶¹ Nancy Wexler was interviewed on the day of the APPG launch, and even enchanted BBC Radio 4 *Today* presenter John Humphries. As Ed Wild recalled, it turned into a longer

⁵⁹ Oral history interview with Tony Wardell.

⁶⁰ Participant 8.

⁶¹ Oral history interview with Tony Wardell.

interview 'I think John Humphries was so entranced by the whole story it lasted three times longer than expected.'⁶²

Participant 4 hoped watching one of the media broadcasts with her brother-in-law would give her a chance to open a dialogue with him: 'he arrived just as Channel 4 news was on and he couldn't avoid it[...]it was my chance to ask him about testing but the subject was brushed aside.'⁶³ This episode clearly illustrates the difficulty of discussing the disease within families.

These snapshots reflect the shared memories of participants as well as the impact of the green tee-shirts everyone wore, the mass of green balloons and the sunshine. A sense of sharing experiences with others was the overriding response. The meanings participants expressed range from those of the political importance of the event to the chance to meet others affected by Huntington's. Each meaning and memory provides a record of that day in June to add to the media reports, journal articles and the record in parliament.

As medical discourse has dominated the history of Huntington's disease in the past, a final comment from Dr Ed Wild emphasises the change in the relationship between clinician, patients and families that has occurred. It exemplifies how events such as the launch of the APPG on Huntington's disease illuminate those affected by the disease giving them an opportunity to stand up and tell their own stories in their own words to politicians, the media, doctors and historians. Ed Wild viewed the launch of the APPG as a challenge by the Huntington's disease community to those historical attitudes:

⁶² Oral history interview with Ed Wild.

⁶³ Participant 5.

We have previously been hidden for reasons, partly of our own making as a community and partly of the professionals who have said to us in the past things like you must not have kids, why don't you go kill yourself, you should be sterilised. This is the way that this community has come to suffer from stigma and our part of the deal as a community was to say we are no longer ashamed this is a thing that is here whether we admit it or not and the first side of curing a problem is acknowledging its existence. The APPG was the best example I know of in any country where people with symptoms of Huntington's disease, people at risk of Huntington's disease, their carers, family members, spouses, partners, kids, people in wheel chairs, people on crutches, people who walked without assistance, researchers, doctors, professionals, MPs, Knights of the Realm and the general public were brought together in a way that educated a lot of people and was also a heartfelt demand for change.⁶⁴



Figure 3 Heading towards Westminster. Source: the author

The meanings and memories created on the day were clearly symbolic for interviewees as an opportunity to stand together and look to the future and change for the better, but also to remember those relatives who had suffered in the past.

⁶⁴ Oral history interview with Ed Wild.

Alexandro Portelli's exploration of *What Makes Oral History Different* discussed the connection between events and meaning and the value of oral history in this relationship and 'what people did, what they believed they were doing, and what they now think they did.'⁶⁵ Oral histories of those who attended the launch of the APPG on Huntington's disease add a layer of memory and meaning to existing reports of the day as well, as considering the significance of the message that Huntington's should be hidden no more. There are a multiplicity of motives for this secrecy and longer in-depth interviews may disclose further opportunities for analysis, but oral histories begin to answer back to the historical dominance of medical discourse and cultural representations in relation to Huntington's disease, voices begin to emerge that may have been silenced in the past and new narratives are added to the history of Huntington's disease.

The complex issue of concealment through history and all over the world was, for one day in June, at least, challenged with openness and sense of freedom, achievement and joy that came with the whole experience of coming together and working for change with others. The future for those facing Huntington's disease is changing and events such as the APPG launch gave a real sense of hope for the future.

⁶⁵ Alexandro Portelli, 'What makes Oral History Different' in R Perks & A Thomson (eds), *The Oral History Reader* (Abingdon, 2006).

Conclusion

The perceptions of those with Huntington's disease and their families has been as complex as the disease itself. That it was spoken of in 'hushed tones' even when George Huntington wrote his paper *On Chorea* hinted at the fear many had of the disease but also perhaps the reactions of others to them. This secrecy was perhaps a practical mechanism to prevent ostracism and isolation from the wider community and as the oral histories demonstrate, hiding has been a strategy employed by many for a host of different reasons. The historical medical discourse revealed the pressures those with Huntington's disease and their relations faced and attitudes of those who studied them; often juxtaposing the omnipotent medical experts against the powerless nameless objects of both their gaze and their calls for intrusive eugenic measures. Whole kin groups were linked with witchcraft, criminality and degeneracy. Such attitudes which have filtered into popular representations of the disease. Yet on 30 June 2010 those whose ancestors had been relentlessly linked with witchcraft and criminality stood together at the heart of government to affirm they would be hidden no more. In the dazzling June sunshine it was a united attempt to challenge the stigma, fear and darkness of the past.



Figure 4 Badge featuring the Hidden No More logo and symbol for Huntington's disease, Source: the author.



Figure 5 Hidden No More lobby 30 June 2010, Source: the author.



Figure 6 Hidden No More 30 lobby June 2010, Source: the author.

Appendix 1 Participant questionnaire.

The purpose of this questionnaire is to supplement an Oral History master's project which will interview some of those who attended the launch of the All Party Parliamentary Group on Huntington's disease 30 June 2010.

The purpose of the study is:

To investigate what motivated people to attend the launch of the All Party Parliamentary Group on Huntington's disease.

- To discover what the title of the launch 'Hidden no More' meant to those who attended.
- To explore the impact of attending the event.

Please write as much or as little as you want.

What is your connection to Huntington's disease?

Before the APPG had you any contact with others affected by HD apart from your family members.

Yes _____

No _____

If yes where? Support groups / conferences / message boards or social media such as Facebook/ other

Did you see anything on the TV or hear anything on the radio or read anything in the newspaper or online about the launch of the All Party Parliamentary Group on Huntington's disease 30June2010.

If yes please give details

Yes _____

No

The theme of the APPG launch was HD was **Hidden No More**.

What does this term mean to you?

Do you think Huntington's disease has been hidden from society?

What do you think are the effects of concealment on families with Huntington's disease?

Are you aware of other diseases which are 'hidden'?

What do you think are the benefits/ drawbacks of Huntington's disease being Hidden No More?

What are you overriding memories of the day?

Gender M F

Age under 21 21-35 36-50 over 50

Thank you for taking the time to complete this questionnaire if you have anything you wish to add please continue on an additional sheet.

The research has been approved by the University of Huddersfield's Research Ethics Committee in the School of Music, Humanities and Media and is supervised by Professor Paul Ward.

Contacts for further information

If you have any queries or questions about this research please do not hesitate to contact me, the best way is email either jsharrison@hotmail.com or u0257651@hud.ac.uk . Alternatively you can call me on xxxxxxxxxxxx

All replies will be confidential however if you would be prepared to participate in a longer recorded interview please add your contact details and I will send you further information.

Appendix 2 Participant Information

Oral Histories of Huntington's Disease families and those who attended the All Party Parliamentary Group on Huntington's Disease 30 June 2010.

Why is the research being done?

I am an oral history research student at the University of Huddersfield and attended the APPG in June 2010. The theme of the day was Hidden No More and oral history gives people who may have been hidden from history an opportunity to tell their story in their own words. I would like to interview you if you attended the APPG in June 2010 both about your memories of the day and reasons for attending, as well as your own experiences of Huntington's disease in your family. Until recently, with the advent of social media, message boards and support groups, family stories have often been hidden and absent from the history of Huntington's disease. This project presents an opportunity for participants to tell these stories.

Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to investigate what motivated people to attend the launch of the All Party Parliamentary Group on Huntington's disease. To discover what the title of the launch Hidden no More meant to those who attended. In addition to talk about the impact of Huntington's disease on families as well as the way it is represented in the media.

Why have I been invited to participate?

You have been chosen to participate because you attended the launch of APPG on Huntington's disease.

Do I have to take part?

Participation is entirely voluntary, it is up to you to decide whether or not to take part. If you decide to participate you will be given a consent form from the University of Huddersfield. If you decide to take part you are still free to withdraw at any time without giving a reason.

What would you be asked to do?

I would like to interview you at a time / location convenient to you. The interview will be informal but cover the topics outlined. An interview would last for between one to two hours but follow up interviews could be arranged. These interviews will be audio-recorded.

What are the benefits of taking part?

The main benefit of taking part is to further understanding of the impact of Huntington's disease on families and the reasons why people attended the APPG launch choosing to be Hidden no More.

There will not be any payment for participants.

Will the interview be confidential?

All the information will remain confidential if requested. Oral history differs from clinical research in that interviewees may participate in order for their own stories to be told. However if anonymity is requested all names and identities will be removed and pseudonyms used in transcripts and written reports. Even though most oral history interviews are generally not anonymous, any interviewee may choose to be anonymous or may choose to become anonymous at any time.

What will happen to the information I give.

Recorded media will be stored on personal and un-networked hard drive in the first instance but will be deposited with an appropriate oral history archive, subject to interviewees' consent. The research will be used in my final dissertation. In addition I will produce a short presentation for those who are interested in the history of Huntington's disease and experiences of it.

Who has reviewed the study?

The research has been approved by the University of Huddersfield's Research ethics Committee.

Contact for further information

If you have any queries or questions about this research please do not hesitate to contact me the best way is email either jsharrison@hotmail.com or u0257651@hud.ac.uk . Alternatively you can call me on 07884036340

Thank you for taking the time to read this and if you would like to take part in the study please e mail or telephone me and I will contact you to arrange a time and place for the interview.

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All interviewees gave permission to use quotations from their interviews in the thesis.

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Oral history interview with Jill Bradley, 6 March 2013, conducted by author in own collection. Jill Has Huntington's disease and family at risk.

Oral history interview with Heth Dagger, 6 March 2013, conducted by author in own collection. Heth is Jill's daughter she has tested negative for the Huntington's gene.

Oral history interview with Mathew Ellison, 23 February 2013, conducted by author in own collection. Mathew has tested positive for the Huntington's gene and has other family members at risk. He founded the Huntington's disease Youth Organisation.

Oral history interview with Mary Howlett, 4 April 2013, conducted, by author in own collection. Mary is a member of the Merseyside branch of the HDA. Her sister's husband and two sons have died as a result of Huntington's and she has other family members at risk.

Oral History Interview with Charles Sabine, 23 February 2013, conducted by author in own collection. Charles has tested positive for the Huntington's gene and his brother has Huntington's. He was instrumental in setting up the APPG and speaks around the world on behalf of Huntington's disease families.

Oral history interview with Cath Stanley, 21 March 2013, conducted by author in own collection. Cath is the CEO of the Huntington's disease Association.

Oral history interview with Tony Wardell, 25 March 2013, conducted by author in own collection. Tony's cared for his wife who has Huntington's before she went into full time residential care. He has other family members at risk.

Oral History interview with Dr Ed Wild, 23 February 2013, conducted by author in own collection. Ed is a neurologist working with patients and in research. He also edits HD Buzz a web site dedicated entirely to Huntington's disease research.

Questionnaire participants:

Participant 1 Female 21-35: Carer for her Husband with Huntington's and with children who are at risk of inheriting the faulty gene.

Participant 2 Female 21-35: Has tested positive for the Huntington's gene and has other family members at risk.

Participant 3 Female under 21: Is at risk of inheriting the gene and has family member with the disease and others at risk.

Participant 4 Female 36-50: Cared for her husband till his recent death.

Participant 5 Male 36-50: Has tested positive for the gene. His mother has Huntington's disease and his daughter is at risk.

Participant 6 Female over 50: Has Huntington's disease. She has siblings with Huntington's disease and children at risk.

Participant 7 Male over 50: Has tested negative for the gene but lost several family members to Huntington's and has others at risk and living with the disease.

Participant 8 Female 21-35: Has tested negative for the gene. Lost her mother recently to Huntington's disease.

Participant 9 Male over 50: Carer for his wife who has Huntington's and recently moved into a care home has other family members at risk.

Participant 10 Female over 50: Has tested negative for Huntington's and is caring for a sibling with the disease.

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