

Obsessive-Compulsive disorder

**A study into the effect on the families and carers of
people with OCD**

Cliff Snelling, November 2004



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1. Introduction

- 1.1 The purpose of this paper is to describe the views and feeling of carers and the families of people with Obsessive-Compulsive disorder (OCD) in the United Kingdom (UK) and to outline their needs in the UK environment. Although there is other work on the subject much of it is based on the situation outside of the UK and while in one respect there are similarities, especially in the emotional aspects, there are significant differences in the approach to OCD and the resources devoted to it. Similarly, much work has been done in respect of the nature of the effect on carers and families and has been carried out largely from a clinical perspective. This study seeks to establish the situation from a carers and families perspective. The data comes directly from carers and family members and is presented as far as possible in the terms expressed by the carers.
- 1.2 The survey follows on from a workshop entitled "*The Reality of Living with an OCD Sufferer*", held at the OCD Action conference in November 2003, Birmingham, UK. The workshop can be considered as stage one of the carers project with this survey as stage two. The third and final stage will be a number of one to one interviews of carers. The purpose of the interviews will be to establish further appropriate information and to research the effect of living with an OCD sufferer on the quality of life of carers and families. Further information on stage three is given in Appendix 2, Methodology.
- 1.3 An analysis of carers views about the treatment and care received or offered to carers and their families and their level of satisfaction is given in chapter 4. It gives an indication on the effect on family members and on family life, also of the financial costs to families/carers.
- 1.4 Chapter 5, Data analysis, illustrates the feelings of carers and families and describes their suffering. This information is given in the context of the survey questionnaire complete with the comments from respondents and gives a comprehensive and detailed overview of the carers perception of the UK situation. It shows the depth of feelings, anxiety, emotion and experiences plus the mental anguish and physical suffering and destruction of family life and strain on relationships. It indicates the damage that OCD can do, not only to the sufferer, but to those around them.
- 1.5 This study comes at a time when greater resources are being put into the National Health Service (NHS) and other fundamental changes to the NHS are being made leading to successes and improvements in various areas of the service.
- 1.6 At the National Institute for Clinical Excellence (NICE) Conference 2004 Birmingham, UK, the Right Honourable John Reid MP, Secretary of State for Health, stated that improvements in the NHS in some areas, notably coronary heart disease and cancer, are better in the UK than in any other country in Europe.

While that is admirable for those conditions there is no perceived improvement in mental health and in OCD in particular. Clearly it is desirable that improvements in mental health will be made and made a priority. One possible way to achieve this would be to lobby the Secretary of State and MPs.

- 1.7 This study seeks to describe the current situation as seen by those around OCD sufferers and to offer a starting point from which to measure change and improvements and to offer a basis to make the case for a better deal and improvements in the treating and care for sufferers and their carers and families.

2. Summary

- 2.1 OCD is a major mental illness in its' own right. However, throughout the health care professions generally there is a massive lack of awareness of the condition and this leads to a lack of diagnosis and subsequent care and treatment in many cases. Clearly diagnosis is the first step in treating or tackling the problem and under diagnosis leads to an underestimation of the extent or scope of the problem.
- 2.2 Moreover, where there is an awareness, there appears to be a lack of understanding, experience and expertise in primary healthcare (GP surgeries) and this coupled with a lack of centres of excellence, or specialist units in many parts of the UK results in a lack of adequate and appropriate attention for sufferers, carers and their families. Where there are specialist units, or referrals to them, the outcome is usually good and compares favourably with other paths.
- 2.3 In a majority of cases any diagnosis, where there is a diagnosis, often takes a long time and due to the perceived lack of understanding, appropriate treatment and referral to a specialist is lacking and where there is referral it appears to be a last resort or where the sufferer or carer has demanded it.
- 2.4 Living with someone who has OCD has a detrimental effect on the quality of life for carers and family members. In addition to the torment of seeing a loved one suffer, many carers suffer considerable stress and anxiety as a result of living with someone with OCD leading to the need for treatment for the carer.
- 2.5 OCD destroys the lives of sufferers and those around them. Suffering can go on for many years and this time is lost never to be regained and can deprive people and families of whole sections of their lives. Clearly, if the condition is successfully treated and managed there would be no secondary effect on carers and families. Sadly that is not the case with only a minority of cases being successfully treated, therefore it is essential to recognise and deal with the implications for carers and families.
- 2.6 Over three quarters of carers and family members become involved in the rituals of their family member OCD sufferer. This can dominate or control them completely and totally destroy the quality of their lives and impose a complete change in lifestyle.
- 2.7 Many GPs and other healthcare personnel are ignorant about the condition. OCD is frequently misdiagnosed with popular diagnoses being "depression", "stress or anxiety", or in the case of adolescents "a teenage thing that they will grow out of". Diagnosis by a doctor can take a very long time, years in some cases, and often only after the carer or sufferer has researched the condition and brought it to the attention of the doctor.

- 2.8 Very often the only information, support and help many carers and families have received is from the OCD organisations, self help groups and their own research via the internet and books on the subject. Many feel very let down by the authorities and an overwhelming majority think that not enough is being done by the health and social services to help families cope.
- 2.9 There are gaping holes in service provision in this area and in mental health generally. In addition to the need for proper and adequate diagnosis, treatment and management of OCD there is a need for support groups for carers and family members in all areas.
- 2.10 It is perhaps best left to the reader to assess the suffering experienced by carers and families from comments which respondents were invited to make. In the present environment, as a society we need to do something to allow carers and families to focus on their grief and sense of loss; loss of a real life, of a relationship, of family life, of reality, of normality. But most of all we need to devote the resources necessary to conquer the scourge of OCD.
- 2.11 A key objective of this study has been to set out, record and to describe the current situation as experienced by those around OCD sufferers. It offers a starting point from which to measure change and improvements and to offer a basis to make the case for a better deal and improvements in the treating and care for sufferers and their carers and families.

3. Conclusions

- 3.1 Living with someone who has OCD has a detrimental effect on the quality of life for carers and family members. Over 80% report a detrimental effect on the quality of life, from moderately to markedly detrimental. Only 3% of carers note no effect on the quality of their lives, however, the majority of those are where the carer does not live with the sufferer. This is a clear cause for concern and where major improvements are needed.
- 3.2 A major reason for the extended symptoms and protracted duration of unmanaged OCD appears to be a general lack of awareness and understanding of OCD and its different aspects, by many GPs and others within the medical profession. Many healthcare professional appear to be unaware of the condition and it is frequently misdiagnosed. Diagnosis by a doctor can take a very long time, years in some cases, and often only after the carer or sufferer has researched the condition and brought it to the attention of the doctor.
- 3.3 Many carers suffer considerable stress and anxiety as a result of living with someone with OCD leading to the need for treatment for themselves. The effect on carers appears to increase with greater severity of illness and the greater the effect on other family members.
- 3.4 Over three quarters of carers and family members become involved in the rituals of their family member OCD sufferer. The ancillary effect of OCD has implications on many carers and family members lives. The extent and the way it affects them varies considerably from a mild inconvenience to a costly, dominating or controlling imposition that can totally destroy the quality of life. Many carers find that their lifestyle is completely changed and subservient to catering to the demands of OCD, and this in addition to the mental anguish and torment of seeing their loved ones suffering.
- 3.5 OCD destroys the lives of sufferers and those around them. Suffering can go on for many years and this time is lost never to be regained and can deprive people and families of whole sections of their lives, therefore it is imperative that everything possible is done to improve the quality of life for sufferers, carers and their families.
- 3.6 Clearly, if the condition is successfully treated and managed there would be no secondary effect on carers and families. Sadly that is not the case with only a minority of cases being successfully treated, therefore it is essential to recognise and deal with the implications for carers and families.
- 3.7 Many GPs and other healthcare personnel are ignorant about the condition. OCD is frequently misdiagnosed with popular diagnoses being “depression”, “stress or anxiety”, or in the case of adolescents “a teenage thing that they will grow out of”.

Information about the condition, treatments and management is well known but it is not widespread within the health and social services with a large proportion of healthcare workers being very ignorant in all matters relating to OCD including its' existence.

- 3.8 The only information, support and help many carers and families have received is from the OCD organisations, self help groups and their own research via the internet and books on the subject. Many feel very let down by the authorities and an overwhelming majority think that not enough is being done by the health and social services to help families cope.
- 3.9 There are gaping holes in service provision in this area and in mental health generally. A large number of suggestions on how to improve the situation are detailed in paragraph 10.2 (data analysis) varying from comments stating that anything is better than nothing to specific needs.
- 3.10 There is a need for support groups. Almost without exception those who had attended support groups noted that it had been of benefit. Support groups are usually local and independent and are sponsored and run by carers and sufferers themselves therefore there will be little, if any, consistency between them. Some means of support and monitoring the groups by the health/social services would help facilitate a consistent high quality service. Support groups should be available in all areas and open to all carers with a mechanism in place to offer carers the opportunity to attend. It is appropriate that there should be separate support groups for carers and sufferers.
- 3.11 Children of parents with OCD can be disadvantaged and may need special attention at school. It is also realistic to assume that support in social aspects of life may be appropriate to give them experience of a "normal" environment.
- 3.12 This survey confirms what has been suspected by families and carers. Surrounding OCD there is a lack of service, understanding, awareness and resources. There is almost certainly an unfair distribution of resources throughout the UK with the absence of specialists or centres of excellence over much of the UK, however further work is needed to confirm and to determine the extent of this.
- 3.13 This survey confirms that OCD is a neglected condition that does not attract the resources and attention that it deserves or the apparent attention of many other conditions. It also confirms that the knock-on effect of OCD on families and carers is generally unrecognised and far greater than ever envisaged or imagined by the healthcare professions and authorities.

4. Findings

- i. This chapter repeats the findings in chapter 5, Data analysis, but with the questions and quantitative data stripped out. *The paragraph numbering is in the order of the questionnaire and using the same numbering as the full analysis in chapter 5 for ease of reference.*
- ii. Not all respondents answered all parts of questions even where it seemed appropriate and this explains why the numbers do not always add up to the total responses and some respondents marked more than one option which will distort the figures. Also, with small figures, rounded to two decimal places, some inaccuracy will occur, however, as the main thrust of this survey is qualitative it is not critical.
 - 1.1 The majority of respondents are parents often of grown up children. While this may be indicative of the membership of OCD Action it also indicates that many parents continue to care for their offspring well into adult age and this is supported by comment received noted elsewhere in this analysis. Indeed, it is a concern of many parents of what will happen to their grown up children when the parents are no longer able to care for them.
 - 2.1 The majority of respondents were adults. There was the opportunity for children who have a parent(s) sufferer to comment, however, there was no response from children up to the age of twelve and just two from teenagers or young persons. This is too little to draw any significant conclusions. It was thought at the outset that it was unlikely to receive a significant number of returns from these sectors, also that the data may be unreliable in the case of young children and subject to ethical concerns (see paragraphs 12.1 and 12.2).
 - 2.2 With over three quarters of carers living with sufferers it is an indicator of the overall effect on carers and their families. The survey did not ask how many persons there are in each family unit (a family unit for the purpose of this research is two or more persons living together in any sort of relationship), however, with an average family unit of 4.5 (National Statistics Online, 2001 census) some indication of the scale of those affected can be seen.
 - 3.1 The results were split into regions in order to determine if there was any difference in the level of service geographically but the sample size is too small to draw accurate conclusions but in total almost 58% considered service levels to be poor.
 - 4.1 Some sufferers have multiple manifestations. Almost all of those with BDD, CSP and TMM also had OCD.
 - 4.2 The average length of time carers have cared for sufferers is 14.63 years. However, as OCD is not curable it is inevitable that this time will increase for many carers

while for others it may not, for example, where sufferers leave the family home. The purpose of this question is to help indicate the overall extent of the effect of living with someone with OCD.

- 4.3 OCD destroys the lives of sufferers and those around them as detailed elsewhere in this report. Suffering can go on for many years and this time is lost never to be regained and can deprive people and families of whole sections of their life, therefore it is imperative that everything possible is done to improve the quality of life for sufferers, carers and their families.
- 5.1 The majority of those who do not become involved with rituals or avoidance behaviour are where the sufferer does not live with the carer, also where other family members are not involved it is because they do not live with the sufferer. Almost all of the parents get involved with rituals/avoidance behaviour. With over three quarters of carers and family members becoming involved in the rituals it can be seen that extent of the ancillary effects of OCD have implications on their lives.
- 5.2 Approximately two thirds of all the carers who become involved in rituals fall within the middle sector of moderately or markedly involved and a similar proportion (68% approx) of family members are similarly affected. Almost a quarter of carers and half that amount of family members are extremely affected. Some 58% of family members become involved with the rituals or avoidance behaviour of sufferers, however, this figure is arbitrary as the "No" answer includes those where there is no other family, also where there are small children too young to become directly involved.
- 5.3 Some respondents noted that one parent or family member is more involved than others. Derisley (work in progress, 2004) notes that frequently in these circumstances parents may not work together and this may be a source of family upset and discomfort. More detailed research about how this affects carers and families and their quality of life will be carried out during the interviews with carers at the next stage of this survey.
- 6.1 Over three quarters of families have made changes in their behaviour or lifestyle to accommodate the ritual or avoidance behaviour of sufferers. Of those some 52% fall in the middle sector of moderately or markedly affected, with some 37% being extremely affected. The majority of those who have not made changes in behaviour or lifestyles are where the sufferer does not live with the carer.
- 6.2 The impact on the quality of life can be huge ranging from stress and physical exhaustion to mental anguish, feelings of guilt and marginalisation. More detailed research about how this affects carers and families and their quality of life will be carried out during the interviews with carers at the next stage of this survey.

- 7.1 Almost two thirds of carers avoid participating in rituals that they consider are interfering too much with family life. The majority of those reporting that they avoid rituals, 55%, find that there is a benefit to family life by doing so. Just over a fifth find it is detrimental and almost a quarter find that it makes no difference to family life. However, less than half find it detrimental to the person with OCD, but less than one fifth find that it is detrimental.
- 7.2 Parents seem to be more involved with their children's rituals than other adults become involved with other adults rituals. The age of children would a relevant factor in the parents involvement and further research is necessary to determine this. Also, where the carer and sufferer do not live together there is less involvement in rituals.
- 8.1 The majority of those having treatment note that it has helped to some degree. A breakdown is given in the table above. The effect on carers appears to be greater with greater severity if the illness.
- 8.2 There appears to be a lack of awareness and understanding of the various aspect of OCD within the medical profession at all levels and in all disciplines. If the sufferer has an aware GP who is knowledgeable and willing to act and arrange for whatever treatment and care is available then a better standard/level of care/treatment is given in comparison to an ignorant GP or one who is unwilling to take the trouble to pursue the matter. Those with good GPs report significantly better outcomes, or a positive future that those with a GP ignorant in OCD and treatments/care available.
- 9.1 An overwhelming majority of carers think that they have not been given enough information. A small number state that this is due to patient confidentiality with one respondent noting that no further information was given when the sufferer reached the age of 18. Many carers noted that they had found information about the condition and treatments themselves.
- 9.2 Inclusion of carers in information sharing varied. Where the sufferer is a minor, parents were given information about the specific case but where the sufferer is an adult there is wide variation in information given. It is important to stress that this question is not just about giving information about individual cases, it is also about the availability of information on OCD generally.
- 9.3 A clear conclusion for the comments received is that many GPs and other healthcare personnel are ignorant about the condition and that OCD was frequently misdiagnosed.
- 9.4 Where sufferers have attended a major centre, e.g. the Maudsley, respondents report that they have been given enough information but almost without exception

they report in answer to question 10 to say that not enough is being done by the health and social services. Respondents also report good improvements in family life at question 14 where the sufferer has been treated at a major centre.

- 9.5 Information about the condition and treatments is well known but it is not widespread within the health and social services with a large proportion of healthcare workers being very ignorant in all matters relating to OCD including its' existence.
- 10.1 An overwhelming majority think that not enough is being done to help families cope. Generally, the more severe the OCD the more likely carers thought that not enough is being done whereas some of those where the OCD is mild thought that enough is being done. Regional differences in service levels could be a factor in the differing views but the sample size of this survey is too small to draw conclusions in this respect. One respondent reporting that enough is being done is resident in France and reports a better service than in the UK. Appendix 3 gives further details of the French situation.
- 11.1 Almost a quarter of carers have attended a support group and the vast majority of those report that it did help. This evidence indicates a clear need for support groups.
- 11.2 Support groups are usually local and independent and are sponsored and run by carers and sufferers themselves therefore there will be little, if any, consistency between them. Some means of support and monitoring the groups by the health/social services would help facilitate a consistent high quality service. Support groups should be available in all areas and open to all carers with a mechanism in place to offer carers the opportunity to attend. It is appropriate that there should be separate support groups for carers and sufferers.
- 11.3 Cooper (Cooper. M. (1995). *Health & Social Work, Vol 20, No 4 1995*) outlines positive gains for family groups participating in a co-dependency group based on a definition of co-dependency that views the families as normal, feeling people who are trying to cope with unremitting stress. While this can be considered to be a form of treatment and is outside of the scope of this study it does demonstrate the difference between voluntary run self help groups and those with some means of professional support and guidance.
- 12.1 No children up to the age of 12 with parent sufferers responded and only 2 adults/teenagers or young persons with parent sufferers responded making the sample size too small to be conclusive, however, from the comments received it is realistic to assume that children with parents with OCD can be disadvantaged and that they may need special attention at school. It is also realistic to assume that

support in social aspects of life may be appropriate to give them experience of a “normal” environment.

- 12.2 Although children up to the age of 12 were given the opportunity to respond there were concerns that this would be inappropriate and any data gathered without validation would be unreliable. However, a number of spouse/partner carer respondents indicated that they had young children and this confirms the obvious deduction that some children have a parent who is a sufferer. Further research is needed to establish the extent of this.
- 13.1 It is encouraging that approximately 80% of sufferers consider that they will improve with treatment. Although this does support the fact that appropriate treatment will help the vast majority of sufferers 18% of carers consider that the sufferer will not improve, however, some of the latter were not having treatment or have had treatment but have stopped. This may be because they consider that treatment will not have the desired effect but some sufferers refuse to acknowledge that they have the condition.
- 14.1 The majority of carers found that knowing the person had OCD, what it is and what can be done about it beneficial and led to an improvement in family life. However, as noted at questions 9 and 10 there is a lack of information and help available from the medical and social services with most respondents reporting that they have had to find information for themselves from various sources notably the OCD patient/carer organisations.
- 14.2 Of those carers who found no, or only a mild improvement many indicated in additional information supplied that the sufferer concerned had severe OCD.
- 14.3 Approximately one-tenth of sufferers have not had the diagnosis made or confirmed by a doctor, although it is assumed that some of those will have the diagnosis confirmed in the future. However, the validity of this response is questionable and appeared to confuse respondents as some ticked “not diagnosed” when a diagnosis was made by a doctor after it had been made by the carer or sufferer. Also, some had ticked “not diagnosed” and stated that the sufferer was having treatment but in these instances it is not known if treatment is based on conventional NHS or alternative methods.
- 14.4 There is some concern about the ability and time taken by doctors to make a diagnosis. This is discussed at question 16. Many carers generally were of the opinion that most people are capable of making the diagnosis and that due to the lateness of diagnosis by the health services, diagnosis by a doctor was merely confirmation.
- 15.2 Many of the skills/traits given by respondents are characteristics of OCD, such as checking, attention to detail and order, perfectionism etc. It is probable, perhaps

due to pride in ones children or partner that skills attributed to the sufferer are done so over enthusiastically.

- 15.3 Depending on the severity of the OCD and the effect on the quality of life of sufferers and carers, then, where the OCD is mild, the skill or trait may be used to advantage. An example is where a senior manager employed a member of staff who appeared to have a mild form of OCD to undertake work requiring thoroughness, patience and sorting and analytical skills. This arrangement was satisfactory to both manager and employee. (It should be noted that the OCD became apparent after employment commenced and was not the reason for employing the person.)
- 16.1 Some respondents give both carer/family and sufferer as the person instrumental in getting a diagnosis. Where the sufferer is a child it is almost always the carer/family who were instrumental. Some respondents reported both the carer and sufferer as instrumental and in some instances no answer is given thus leading to a discrepancy in the figures. However, almost three quarters of respondents report that it was the carer which indicates that carers have observed a problem and have taken action. Many carers report that only persistent visits and complaints to GPs resulted in appropriate investigation and final diagnosis confirming the diagnosis of the carer. There is some concern about the ability and time taken by doctors to make a diagnosis (see paragraphs 14.3 and 14.4).
- 16.2 Well over half of sufferers have been diagnosed by carers and more than one-third were diagnosed by the sufferers themselves.
- 16.3 This raises the question of why it takes so long for doctors to make a diagnosis. In part this could be due to delays in getting the sufferer to visit their GP, however, a number of respondents considered that the delay was the result of a lack of awareness of the condition by GPs. This is in stark contrast to the situation in France where awareness is high and a diagnosis is made soon after the patient presents and where treatment can be started within a very short time (see appendix 3 – The French Situation).
- 17.1 Almost two-thirds of respondents report a high cost of living with someone with OCD. Many of the No's include where sufferer does not live with carer and where there usually is no cost to the carer. Almost half give the costs as moderate to high. Costs are subjective and relate to the relative wealth and income of carers/families therefore minimal, moderate and high have been used to express the rating of costs rather than use cost bands expressed in an amount of money. Some comments give the actual costs incurred.
- 17.2 Costs incurred range fro the cost of medication and treatment to the cost of purchasing additional cleaning materials and replacing “contaminated” items such as clothing and other everyday items that are thrown away after only one use. A

major high cost is in lost opportunity either from the sufferer not being able to work or the carer giving up work to look after the sufferer. Costs also include having children live with grandparents and in more extreme cases respondents report such things as frequent house moving and scrapping cars.

- 18.1 Approximately 95% report a detrimental effect on the quality of life, from moderately to markedly, with all but one reporting an improvement. With less than 3% noting no effect, and most of those where the carer does not live with the sufferer, this is a clear cause for concern and where major improvements are needed.
- 18.2 The impact on the quality of life can be huge ranging from stress and physical exhaustion to mental anguish, feelings of guilt and marginalisation. More detailed research about how this affects carers and families and their quality of life will be carried out during the interviews with carers at the next stage of this survey.
- 18.3 Comments were received (see Chapter 5, Data analysis paragraph 18.3) which demonstrate the detrimental effect on the quality of life of carers. While many of the comments relate to individual carers, the effect is often spread to all family members. This can be further enhanced where the primary carer is a parent and is caring, in a family sense, for other family members.
- 19.1 Just over one-third of carers and family members have received treatment with almost two-thirds reporting that it had helped. It is not known why the majority have not received treatment although a small number report that it has been offered but not accepted. Many carers indicate a lack of awareness or willingness by GPs and social services to acknowledge or accept that carers and families may need some support or treatment.
- 19.2 Carers and families suffer from unremitting stress. The co-dependency group model referred to in paragraph 11.3 and outlining positive gains may be an appropriate treatment.
- 20.1 A number comments were received (see Chapter 5, Data analysis, paragraph 20.1) The comments indicate significant shortcomings in the medical and social services and little imagination is required to determine what is needed.
- 21.1 Comments were invited about what carers would like to see done to improve their lives. They are given at Chapter 5, Data analysis, paragraph 21.1

5. Data analysis

Introduction to this chapter

- 5.1 This data analysis chapter is presented in the order of the questionnaire *and using the same numbering as on the questionnaire*. With each question, the quantitative results giving the actual numbers responding to the question and the percentage of the total for each answer is given. Where an answer is further broken down depending on the answer (e.g. yes/no, If yes etc.) then the actual numbers are those answering yes and the percentage is the percentage of those answering yes.
- 5.2 Not all respondents answered all parts of questions even where it seemed appropriate and for this reason the numbers and percentage calculations do not always add up to the total responses. Also, some respondents marked more than one option which will distort the figures. It was not always possible to determine which option the respondent wished to choose and make a correction therefore in these instances both options were included.
- 5.3 Where percentages have been given they are rounded to two decimal places. With the small figures involved and combined with rounding some inaccuracy will occur, however, the figures although very largely accurate remain indicative and as the main thrust of this survey is qualitative slight inaccuracies are not critical.
- 5.4 Overall service rating: In order to achieve consistency this was assessed as part of the analysis and evaluation process using respondents' comments. Where there was insufficient information or uncertainty the rating is defaulted to satisfactory. Perceived level of satisfaction would appear to depend on personal expectations and much of this seems to be based on age and circumstances surrounding upbringing. Older persons seemingly from "working class" backgrounds have a lower level of expectations than others. Unless there is a specific comment or indicator about service rating the key factors used to assess the rating are the extent that the sufferer considers he/she will improve and the level of information and help given to carers. Generally, the lesser the severity of OCD the greater the satisfaction with treatment.
- 5.5 Electronic responses from OCD websites frequently give far less qualitative information with respondents just ticking the tick boxes. This makes it difficult/impossible to assess the service rating by the above criteria of assessment, therefore these responses fall in the satisfactory category by default and thus tend to distort the overall assessment. However, as the number of electronic responses is relatively small the effect would be minimal.
- 5.6 The majority of respondents are parents often of grown up children. There is no obvious reason for this but it is assumed that parents continue to care for their

offspring well into adult age; indeed it is a concern of many of what will happen to their grown up children when they are no longer able to care for them.

- 5.7 Further trawls through the data could draw out more detailed information where a more detailed breakdown of various aspects is desired.
- 5.8 Where comments from respondents are included they are in response to where comments were invited. In some instances respondents have added comments to answers where comments were not invited and where appropriate these are included. As far as possible a representative cross section of comments received giving both positive and negative views are included. Where a number of respondents gave the same or similar comment having the same meaning, e.g. in respect of information availability, this is recorded only once.

PART ONE – about you

1. What is your relationship to the person with OCD?

Spouse/partner	26	31.33%
Parent	48	57.83%
Son/daughter	5	6.02%
Brother/sister	3	3.61%
Other relation	1	1.20%
Friend	1	1.20%

- 1.1 The majority of respondents are parents often of grown up children. While this may be indicative of the membership of OCD Action it also indicates that many parents continue to care for their offspring well into adult age and this is supported by comment received noted elsewhere in this analysis. Indeed, it is a concern of many parents of what will happen to their grown up children when the parents are no longer able to care for them.

2. Please tick the box that best describes you:

Child up to the age of 12	0	0%
Teenager or young person	2	2.41%
Adult	80	96.39%
Not given	2	2.41%

Do you live with the OCD sufferer?

Yes	62	74.70%
No	17	20.48%
Not given	4	4.82%

- 2.1 The majority of respondents were adults. There was the opportunity for children who have a parent(s) sufferer to comment, however, there was no response from children up to the age of twelve and just two from teenagers or young persons. This is too little to draw any significant conclusions. It was thought at the outset that it was unlikely to receive a significant number of returns from these sectors, also that the data may be unreliable in the case of young children and subject to ethical concerns (see paragraphs 12.1 and 12.2).
- 2.2 With over three quarters of carers living with sufferers it is an indicator of the overall effect on carers and their families. The survey did not ask how many persons there are in each family unit (a family unit for the purpose of this research is two or more persons living together in any sort of relationship), however, with an average family unit of 4.5 (National Statistics Online, 2001 census) some indication of the scale of those affected can be seen.

3. Please give the area where you live:

Regions	Total by Region	Overall service rating by region		
		Poor	Satisfactory	Good
London	10	5	5	0
East Midlands	7	5	2	0
East of England	10	6	3	1
North East	4	3	1	0
North West	6	6	0	0
South East	15	7	7	1
South West	9	5	4	0
West Midlands	5	3	2	0

Yorkshire & Humber	4	2	2	0
Wales	4	2	2	0
Scotland	5	2	3	0
N. Ireland	2	1	1	0
Not given	<u>2</u>	<u>1</u>	<u>1</u>	<u>0</u>
Total	83	48 = 57.83%	33 = 39.76%	2 = 2.41%
<u>Overseas</u>				
France	1			

3.1 The results were split into regions in order to determine if there was any difference in the level of service geographically but the sample size is too small to draw accurate conclusions but in total almost 58% considered service levels to be poor.

4. Which manifestation, or type of OCD, does the person with OCD have?

OCD	79	95.18%
BDD	4	4.82%
CSP	5	6.02%
TMM	4	4.82%

How long has the person had the condition?

Years	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
No.	3	1	5	4	5	4	3	6	15	8	1	3	3	1	5
Years	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
No.	1	1	0	1	6	1	0	1	0	0	1	0	1	0	4
Years	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45
No.	0	0	0	1	1	0	1	0	0	3	0	0	1	0	0

- 4.1 Some sufferers have multiple manifestations. Almost all of those with BDD, CSP and TMM also had OCD.
- 4.2 The average length of time carers have cared for sufferers is 14.63 years. However, as OCD is not curable it is inevitable that this time will increase for many carers while for others it may not, for example, where sufferers leave the family home. The purpose of this question is to help indicate the overall extent of the effect of living with someone with OCD.
- 4.3 OCD destroys the lives of sufferers and those around them as detailed elsewhere in this report. Suffering can go on for many years and this time is lost never to be regained and can deprive people and families of whole sections of their life, therefore it is imperative that everything possible is done to improve the quality of life for sufferers, carers and their families.

PART TWO – about the effect on the family of the person with OCD

5. Do you become involved in the rituals or avoidance behaviour of the person with OCD? (e.g. do you do things that are part of the rituals or are demanded or requested by the person with OCD)

Yes	67	80.72%
No	16	19.27%

a. If Yes, to what extent do you consider you are involved?

Mildly	13	19.40%
Moderately	25	37.31%
Markedly	21	31.34%
Extremely	10	14.93%

b. To what extent does this affect your life?

Not at all	1	1.49%
Mildly	12	17.91%
Moderately	19	28.36%
Markedly	23	34.33%
Extremely	13	19.40%

c. To what extent does your involvement in the rituals or avoidance behaviours affect the lives of other family members?

Not at all	6	8.96%
Mildly	15	22.39%
Moderately	19	28.36%
Markedly	16	23.88%
Extremely	7	10.45%

d. Do other members of your family become involved with the rituals or avoidance behaviour of the person with OCD?

Yes	39	58.21%
No	24	35.82%

- 5.1 The majority of those who do not become involved with rituals or avoidance behaviour are where the sufferer does not live with the carer, also where other family members are not involved it is because they do not live with the sufferer. Almost all of the parents get involved with rituals/avoidance behaviour. With over three quarters of carers and family members becoming involved in the rituals it can be seen that extent of the ancillary effects of OCD have implications on their lives.
- 5.2 Approximately two thirds of all the carers who become involved in rituals fall within the middle sector of moderately or markedly involved and a similar proportion (68% approx) of family members are similarly affected. Almost a quarter of carers and half that amount of family members are extremely affected. Some 58% of family members become involved with the rituals or avoidance behaviour of sufferers, however, this figure is arbitrary as the "No" answer includes those where there is no other family, also where there are small children too young to become directly involved.
- 5.3 Some respondents noted that one parent or family member is more involved than others. Derisley (work in progress, 2004) notes that frequently in these circumstances parents may not work together and this may be a source of family upset and discomfort. More detailed

research about how this affects carers and families and their quality of life will be carried out during the interviews with carers at the next stage of this survey.

5.4 The following is a selection of comments received which is a guide to the extent and depth of the experiences and feelings of carers and families:

- *I, as mother, am the only one affected by my daughter's rituals. Good for her, but absolute hell for me.*
- *Carer must wash hands frequently and not touch anything with feet if shoes worn.*
- *Accumulates large quantities of books which causes inconvenience to the family.*
- *Someone must be with sufferer at all times.*
- *Relationship conflicts.*
- *Tiered and emotionally exhausting.*
- *Destroys family life.*
- *Sufferer confined himself to home putting additional chores/stress on family members*
- *Family goes along with rituals to keep the peace.*
- *Rituals usually cause family arguments.*
- *The rituals are very irritating and we just want some peace.*
- *She not only checks, but keeps asking us to check, and then has to check if we have checked.*
- *We live in France where there is a different approach to OCD.*
- *Other children feel neglected and resentful.*
- *Uses illness to control, thus causing arguments.*
- *The family were frustrated, angry and exhausted both mentally and physically.*
- *The family either suffered weight loss or overate and gained weight.*
- *He is sad, irritable and picks on small things.*
- *Our son now displays many of his father's characteristics [hoarding].*
- *Sufferer continually seeks reassurance.*
- *We have to repeatedly answer the same question.*
- *Insists on using only paper tissues for drying after washing and has a special bin to place used tissues in.*
- *Will not sit on the same sofa as others.*
- *It is just me and my Mum as my Dad left years ago.*
- *All relative and acquaintances are expected to follow wife's OCD rules.*
- *Attempts to avoid participating in rituals become subject to violence and threats from the sufferer.*
- *It is just hell to see the destruction of a life being perpetuated by pandering to OCD and compliance with insane and self destroying rituals.*
- *My wife has to watch me shower and comments on how I wash.*
- *I cannot use the lavatory in the house if I have used another elsewhere.*
- *I cannot go to bed without having a shower.*
- *When we clean or wash towels I have to clean all the doors in the house.*
- *We can't remember what it is like to have a normal conversation with him as we have to wait until he has finished repeating himself before we can continue.*
- *His brother feels as if he's lost his brother.*
- *Almost everything we do has to be planned, even the smallest things such as shopping. Nothing we do is really spontaneous.*
- *We minimise the occasions we go out because my wife does not want others to know about her condition.*
- *It is often easier and quicker to accept the requirements of OCD than to debate the consequences of not carrying them out.*
- *I now to some extent think along the lines of the OCD as it allows me to shelter from intrusive questions.*
- *It is now my responsibility to do all the cooking, cleaning and household chores including the cleaning and other ritual requirements.*

- *I feel guilty if I take time out to do hobbies with friends.*
- *I care for my wife and son 24 hours a day every single day of my life. If this was cancer or some other disease I would get some help, support and some respite. So **** you Thatcher for destroying mental health services and condemning me to a life of pure hell!*
- *During weekly visits he can become very aggressive.*
- *There is a lot of anger, distress and highly charged emotion around and the children hear a lot of conflict.*
- *We try to keep ritual and avoidance behaviour as far as possible from the children.*
- *We have to avoid references to “bad” topics and to move books out of the house.*
- *My wife is a hoarder and more than half of the house is unusable.*
- *The children have had to go to live with their grandparents. Life is on hold, it is just a nightmare.*
- *The whole family gets involved for the “sake of peace” and to avoid anger and abuse and hysterical and self harming behaviour by the sufferer.*
- *It’s like walking on egg shells to keep the sufferer happy.*

6. Have you and your family made changes in your behaviour or your lifestyle to accommodate the rituals and demands of the person with OCD? (e.g. has a family member had to give up work to look after the person with OCD, or has there been severe disruption to family life and routines or the inability to change or to take holidays?)

Yes	65	78.31%
No	20	24.10%

a. If Yes, how much has this affected you and your family?

Mildly	4	6.15%
Moderately	15	23.08%
Markedly	19	29.23%
Extremely	24	36.92%

- 6.1 Over three quarters of families have made changes in their behaviour or lifestyle to accommodate the ritual or avoidance behaviour of sufferers. Of those some 52% fall in the middle sector of moderately or markedly affected, with some 37% being extremely affected. The majority of those who have not made changes in behaviour or lifestyles are where the sufferer does not live with the carer.
- 6.2 The impact on the quality of life can be huge ranging from stress and physical exhaustion to mental anguish, feelings of guilt and marginalisation. More detailed research about how this affects carers and families and their quality of life will be carried out during the interviews with carers at the next stage of this survey.
- 6.3 The following is a selection of comments received which is a guide to the extent and depth of the experiences and feelings of carers and families resulting from changes in behaviour and lifestyle.
- *Cannot take holidays.*
 - *Have no social life.*
 - *Children excluded form social life.*
 - *Feeling of guilt.*
 - *Burden of extra household duties and work.*
 - *Stress re affect on children.*
 - *Feel like a “single parent.”*
 - *Husband/wife have to take separate holidays.*
 - *Have to make special arrangements to accommodate rituals/obsessions.*

- *Impossible to function as a family.*
- *Older children have moved out of the family home because of this.*
- *Cannot have visitors to the house.*
- *Greater understanding of the condition has helped us.*
- *We make sure that he is not left at vulnerable times or exposed to social occasions that may cause distress.*
- *My mother has had OCD for all of my life, so family life has always incorporated OCD.*
- *Taking a holiday was more stressful than staying at home.*
- *We curtailed holidays from one week to a few days.*
- *We were afraid to leave him at home alone with his sister.*
- *We have done almost nothing as a family for years.*
- *I can no longer work as I need to be at home to support my daughter.*
- *Our son's OCD has caused a great deal of sorrow.*
- *The hard part is to witness his anxiety and realise it is his "fight".*
- *Very hard for parents not to be able to "make things better", to stay strong and supportive, when inside we are heart broken to know life is such a struggle for him.*
- *Many tears shed, holding back to a private moment is very difficult.*
- *I suffered a mental breakdown because of this problem.*
- *I have had to give up work.*
- *It is difficult to have other people in the house.*
- *I am ashamed and embarrassed.*
- *Son has sexual thoughts about mother which disgusts him.*
- *He needs constant reassurance that he hasn't touched me and is very uncomfortable in my company [mother/son].*
- *Does not tolerate my laundered clothes being in contact with his clothes.*
- *Turns his head away when I talk to him because of moisture particles from my mouth.*
- *We spent a great deal of time and patience helping him.*
- *We are concerned about possible medication impact on his personality.*
- *Family days out are extremely difficult.*
- *Arranging child care around the needs of therapy sessions.*
- *He will not go away with friends.*
- *It has meant adapting an irrational way of thinking and living.*
- *Anything new is a great source of anxiety.*
- *We are always on tender hooks and afraid that any "normal" activity will cause another upset and another new obsession and ritual.*
- *We cannot prepare food in the house, generally we eat out but can eat food in the house that has been prepared elsewhere.*
- *Washing backs up as we can only wash one load a day.*
- *Our sex life is infrequent.*
- *Anxiety is always just around the corner.*
- *We go to some lengths to prevent others including family becoming aware of the problem.*
- *The home is chaotic and proper routines are not there.*
- *As parents we spend too much time together as if stuck together with shame.*
- *Our family life has been devastated.*
- *We have to avoid conflict.*
- *The sufferer becomes very negative and aggressive orally which always spoils social events.*

7. Do you avoid participating in rituals if you consider that they are interfering too much with family life?

Yes	53	63.86%
No	22	26.51%

a. If Yes, do you consider the outcome to show:

Short term benefits	19	35.85%
Long term benefits	10	18.87%
It is detrimental	13	24.53%
No difference	12	22.64%

b. Do you think this has been detrimental to the person with OCD?

Not at all	14	26.42%
Mildly	13	24.53%
Moderately	10	18.87%
Markedly	3	5.66%
Extremely	6	11.32%

7.1 Almost two thirds of carers avoid participating in rituals that they consider are interfering too much with family life. The majority of those reporting that they avoid rituals, 55%, find that there is a benefit to family life by doing so. Just over a fifth find it is detrimental and almost a quarter find that it makes no difference to family life. However, less than half find it detrimental to the person with OCD, but less than one fifth find that it is detrimental.

7.2 Parents seem to be more involved with their children's rituals than other adults become involved with other adults rituals. The age of children would a relevant factor in the parents involvement and further research is necessary to determine this. Also, where the carer and sufferer do not live together there is less involvement in rituals.

7.3 The following is a selection of comments received which is a guide to carers and families experiences of avoidance in participating with rituals. Comments were not asked for on the questionnaire but the following were received and it was considered appropriate to include them here.

- *I have to make a judgement as to whether partner is up to confrontation.*
- *Long term benefits outweigh the short term discomfort.*
- *It is difficult to avoid participation as the sufferer becomes very aggressive.*
- *I don't avoid, I fit things into daily routine.*

8. Is the person with OCD having any treatment?

Yes	61	73.49%
No	23	27.71%

If Yes, how much has it helped?

Not at all	4	6.56%
Mildly	19	31.15%
Moderately	14	22.95%
Markedly	16	26.23%
Extremely	7	11.48%

8.1 The majority of those having treatment note that it has helped to some degree. A breakdown is given in the table above. The effect on carers appears to be greater with greater severity if the illness.

8.2 There appears to be a lack of awareness and understanding of the various aspect of OCD within the medical profession at all levels and in all disciplines. If the sufferer has an aware

GP who is knowledgeable and willing to act and arrange for whatever treatment and care is available then a better standard/level of care/treatment is given in comparison to an ignorant GP or one who is unwilling to take the trouble to pursue the matter. Those with good GPs report significantly better outcomes, or a positive future that those with a GP ignorant in OCD and treatments/care available.

8.3 The following is a selection of comments received relating to treatment for sufferers.

- *Considered to be free of OCD at one time but it returned and was more powerful than before.*
- *Sufferer hates seeing doctors and worries about appointments for weeks beforehand.*
- *Counselling was detrimental – CBT was helpful.*
- *Drug therapy was not helpful as no one [medical services] understood the problem.*
- *CBT has made our life 100% better.*
- *Counselling did not work.*
- *With my personal help he has reduced bathroom rituals from 12 hours to 1 ½ hours.*
- *Medication helps but she can still have periods where the OCD is very bad.*
- *He had a course of CBT and is so much better and he is off medication which didn't help much.*
- *He became a Christian 3 or 4 years ago and people praying for him helps.*
- *Has had OCD for so long she is now "institutionalised".*
- *Much of the treatment has not helped at all.*
- *We are very grateful to all those who have worked to ease our son's suffering.*
- *Drugs work, therapy doesn't.*
- *His psychologist does a lot of talking but achieves very little.*
- *The therapy sessions have helped the child with OCD, also us as parents to have a better understanding of the illness.*
- *Unable to engage with NHS services. No sensible help is being offered anyway!*
- *Private counselling was disastrous as the "professional" involved really had no idea how to deal with the illness and made things worse, but didn't have any problems charging £30 for a ¾ hour session!*
- *On the outside medication seem to make a difference but it doesn't solve the problems that she is facing on the inside.*
- *He is given medication seemingly only to keep off the backs of the healthcare professionals and out of the GP's surgery.*
- *Its' no good the doctors just blaming the person for having OCD and the psychiatrists blaming them for their behaviour!*
- *She stopped taking medication when she became pregnant for fear of harming the baby but her OCD became markedly worse.*
- *The changeover from child to family psychiatry and integrating to the adult mental health system was very distressing with little support from the NHS in the grey area of 16 to 18 year olds.*

9. Do you think that you have been given enough information about OCD from the health or social services and any treatment or care the person with OCD is receiving?

Yes	20	24.10%
No	63	75.90%

If No, what information about OCD would you like to receive?

9.1 An overwhelming majority of carers think that they have not been given enough information. A small number state that this is due to patient confidentiality with one respondent noting that no further information was given when the sufferer reached the age of 18. Many

carers noted that they had found information about the condition and treatments themselves.

- 9.2 Inclusion of carers in information sharing varied. Where the sufferer is a minor, parents were given information about the specific case but where the sufferer is an adult there is wide variation in information given. It is important to stress that this question is not just about giving information about individual cases, it is also about the availability of information on OCD generally.
- 9.3 A clear conclusion for the comments received is that many GPs and other healthcare personnel are ignorant about the condition and that OCD was frequently misdiagnosed.
- 9.4 Where sufferers have attended a major centre, e.g. the Maudsley, respondents report that they have been given enough information but almost without exception they report in answer to question 10 to say that not enough is being done by the health and social services. Respondents also report good improvements in family life at question 14 where the sufferer has been treated at a major centre.
- 9.5 Information about the condition and treatments is well known but it is not widespread within the health and social services with a large proportion of healthcare workers being very ignorant in all matters relating to OCD including its' existence.
- 9.6 The following is a selection of comments received:
- *The school doctor was totally ignorant of the condition. She insisted that my daughter would grow out of it.*
 - *All doctors dealing with teenagers should have information about OCD.*
 - *The boarding school was fortunate not to have a suicide on their hands.*
 - *How to give support.*
 - *What support is available via services.*
 - *Information about the condition, treatment and drugs.*
 - *Advice on how to emphasis with the sufferer.*
 - *How to cope with anger and frustration.*
 - *Where to go for information and help - had to find out for ourselves.*
 - *GPs have no knowledge.*
 - *Specialists are unwilling to share information.*
 - *Once the sufferer reached the age of 18 I was excluded, although he still needed my help.*
 - *Newsletters.*
 - *Information from OCD clinic.*
 - *Information on how to help me.*
 - *Information on how best to help my son.*
 - *Information about the condition that the medical profession has that I had to find out for myself.*
 - *No information was given and her brothers and sisters thought she was attention seeking.*
 - *The psychologist recommended a book and from that I was able to suggest which medications to try and how long to take them for.*
 - *I've had to source it myself.*
 - *How this condition is affecting function and behaviour.*
 - *How I can relax the sufferer at bad times.*
 - *There is only American information about hoarding.*
 - *The leading specialist now says that his treatment methods don't work!*
 - *Hoarding is much more common than people realise.*
 - *Anything!*
 - *I have shared information with NHS staff!*
 - *How to carry on living a normal life despite OCD.*

- *They don't really appreciate how impossible it is to live with a severe OCD sufferer.*
- *How to help and support and not just "enable".*
- *How do you get information from a so called GP who has never heard of OCD and is completely ignorant about this and most medical matters.*
- *Things had to get very bad before we received any treatment and then there was very little information.*
- *How to overcome the fear.*
- *Easier access to specialists and to be able to approach them directly.*
- *GP's should be more responsive to pleas for help.*
- *I need to know how I can cope.*
- *Why can't treatment be given on a case by case basis rather than on a first come first served basis.*
- *Coping strategies.*

10. Do you think that enough is being done by the health or social services to help families cope with the difficulties arising from a family member having OCD?

Yes	6	7.23%
No	75	90.36%

If No, what else would you suggest?

- 10.1 An overwhelming majority think that not enough is being done to help families cope. Generally, the more severe the OCD the more likely carers thought that not enough is being done whereas some of those where the OCD is mild thought that enough is being done. Regional differences in service levels could be a factor in the differing views but the sample size of this survey is too small to draw conclusions in this respect. One respondent reporting that enough is being done is resident in France and reports a better service than in the UK. Appendix 3 gives further details of the French situation.
- 10.2 This question drew a large number of suggestions to improve the situation varying from comments stating that anything is better than nothing to specific needs. The following comments give the strongest indication that there are gaping holes in service provision in this area and in mental health generally.
- *More/some information, advice and support.*
 - *More individual counselling, less group counselling.*
 - *Greater awareness of the condition by the services and staff.*
 - *Shorter waiting time to see psychiatrist/practitioners and more frequent appointments.*
 - *Earlier diagnosis before condition becomes chronic.*
 - *OCD charities should be funded to provide back up to the NHS.*
 - *They don't know who or where to send you for help.*
 - *Greater awareness in schools and generally to the public.*
 - *More tolerance needed from the public to stop the abuse that sufferers are subjected to.*
 - *Written information.*
 - *Something to alleviate family tensions.*
 - *Her OCD has led to family break-ups and nearly led to the parents breaking up.*
 - *Families need information about OCD, its effects and available treatment.*
 - *Families need support and encouragement.*
 - *Families need to know how to get in touch with self help groups and OCD charities etc.*
 - *Our reaction was driven entirely through fear and this made us behave abnormally in a way that accommodated the illness.*
 - *We've learned the hard way through years of experience.*
 - *We have been fortunate to have good doctors.*

- *A special health channel on television.*
- *How thought processes work and how OCD interferes with them.*
- *Information on how to find a therapist.*
- *There needs to be far greater understanding and acknowledgement by GPs etc.*
- *Support for sufferer!*
- *Support groups set up for a range of age groups.*
- *A mentoring system within regions for carers/families/friends.*
- *Contact with other families or carers.*
- *Need to have someone to turn to or ask for help especially after 5.00pm when there is nothing for children.*
- *A joint consultation with the doctor [sufferer/carer].*
- *Anything is better than nothing.*
- *There needs to be available supported independent housing for young adults to have a chance to learn how to live rather than blaming those around them for their feelings!*
- *NHS as social services staff must be made aware of OCD and its effect on sufferers and their families.*
- *There is very little support for the carer. I don't think my relationship would have survived if it were not for my church, friends and family.*
- *It would be nice to be given assurance that this will not go on for ever.*
- *I have never been offered any support opportunities.*
- *Face to face support for the whole family.*
- *Helping him would help us.*
- *Posters etc in the doctor's surgery.*
- *That they show an interest.*
- *Support, encouragement plus some help with ways to cope.*
- *Support for the whole family is needed.*
- *We remain unknown and unheard. It is as though OCD and mental disorders are still taboo, even in this modern world.*
- *After years of trying it took until things became very desperate before anyone seemed to listen.*

11. Have you attended a family or other support group?

Yes	19	22.89%
No	53	63.86%

If Yes, how much did it help?

Not at all	1	5.26%
Mildly	9	47.37%
Moderately	7	36.84%
Markedly	2	10.53%
Extremely	1	5.26%

- 11.1 Almost a quarter of carers have attended a support group and the vast majority of those report that it did help. This evidence indicates a clear need for support groups.
- 11.2 Support groups are usually local and independent and are sponsored and run by carers and sufferers themselves therefore there will be little, if any, consistency between them. Some means of support and monitoring the groups by the health/social services would help facilitate a consistent high quality service. Support groups should be available in all areas and open to all carers with a mechanism in place to offer carers the opportunity to attend. It is appropriate that there should be separate support groups for carers and sufferers.

- 11.3 Cooper (Cooper. M. (1995). *Health & Social Work, Vol 20, No 4 1995*) outlines positive gains for family groups participating in a co-dependency group based on a definition of co-dependency that views the families as normal, feeling people who are trying to cope with unremitting stress. While this can be considered to be a form of treatment and is outside of the scope of this study it does demonstrate the difference between voluntary run self help groups and those with some means of professional support and guidance.

12. If one (or both) of your parents has OCD how does this affect you?

Not at all	0	0.00%
Mildly	1	50.00%
Moderately	1	50.00%
Markedly	0	0.00%
Extremely	0	0.00%

Does it affect:

Work or schoolwork (including homework)?

Yes	0	0.00%
No	2	100.00%

leisure time?

Yes	2	100.00%
No	0	0.00%

bringing friends home?

Yes	2	100.00%
No	0	0.00%

- 12.1 No children up to the age of 12 with parent sufferers responded and only 2 adults/teenagers or young persons with parent sufferers responded making the sample size too small to be conclusive, however, from the comments received it is realistic to assume that children with parents with OCD can be disadvantaged and that they may need special attention at school. It is also realistic to assume that support in social aspects of life may be appropriate to give them experience of a “normal” environment.

- 12.2 Although children up to the age of 12 were given the opportunity to respond there were concerns that this would be inappropriate and any data gathered without validation would be unreliable. However, a number of spouse/partner carer respondents indicated that they had young children and this confirms the obvious deduction that some children have a parent who is a sufferer. Further research is needed to establish the extent of this.

- 12.3 The following comments were received.

- *My education has been important to me and I would not let my mum’s OCD affect this.*
- *She pesters me with OCD things which makes it difficult to concentrate.*
- *She constantly rings me on my mobile to check things.*
- *Bringing friends home isn’t a problem, but bringing boyfriends home is.*
- *OCD **does** affect his school work, leisure time and relationship with friends.*

13. Do you think that the person with OCD considers that he/she will improve with treatment and if so to what extent?

Will improve a little	34	40.96%
Will improve a lot	24	28.92%
Will be fully cured	8	9.64%
Will not improve	15	18.07%

13.1 It is encouraging that approximately 80% of sufferers consider that they will improve with treatment. Although this does support the fact that appropriate treatment will help the vast majority of sufferers 18% of carers consider that the sufferer will not improve, however, some of the latter were not having treatment or have had treatment but have stopped. This may be because they consider that treatment will not have the desired effect but some sufferers refuse to acknowledge that they have the condition.

13.2 The following comments were given about those who consider they will not improve.

- *Refuses to discuss the condition.*
- *Will not have treatment consistently.*
- *Daughter says she will never be better.*
- *Will not acknowledge the problem.*
- *He has no hope at all of improving and frequently talks about suicide.*
- *He has become happy with his OCD and accepts it as part of his character. He does everything to accommodate it and expects others to do the same.*

14. Has there been an improvement in family life since the person was diagnosed as having OCD?

Yes	42	50.60%
No	33	39.67%
Not diagnosed (by a doctor)	9	10.84%

If Yes, how has it helped to know that the person has OCD?

Not at all	4	9.52%
Mildly	7	16.67%
Moderately	6	14.29%
Markedly	12	28.57%
Extremely	18	42.86%

14.1 The majority of carers found that knowing the person had OCD, what it is and what can be done about it beneficial and led to an improvement in family life. However, as noted at questions 9 and 10 there is a lack of information and help available from the medical and social services with most respondents reporting that they have had to find information for themselves from various sources notably the OCD patient/carer organisations.

14.2 Of those carers who found no, or only a mild improvement many indicated in additional information supplied that the sufferer concerned had severe OCD.

14.3 Approximately one-tenth of sufferers have not had the diagnosis made or confirmed by a doctor, although it is assumed that some of those will have the diagnosis confirmed in the future. However, the validity of this response is questionable and appeared to confuse respondents as some ticked "not diagnosed" when a diagnosis was made by a doctor after it had been made by the carer or sufferer. Also, some had ticked "not diagnosed" and stated that the sufferer was having treatment but in these instances it is not known if treatment is based on conventional NHS or alternative methods.

14.4 There is some concern about the ability and time taken by doctors to make a diagnosis. This is discussed at question 16. Many carers generally were of the opinion that most

people are capable of making the diagnosis and that due to the lateness of diagnosis by the health services, diagnosis by a doctor was merely confirmation.

14.4 The following is a selection of comments received which should be read in conjunction with those at question 16.

- *Late diagnosis has been detrimental.*
- *Unaware of OCD for 13 years until problems reached crisis point.*
- *Emotional guilt for not knowing about OCD and how to help.*
- *Family life improved only after sufferer moved away.*
- *GP not helpful or informative. Had little or no knowledge of OCD.*
- *After months of treatment the therapist never informed us what it was, we though we were going mad.*
- *Eventually they diagnosed OCD – Hip, Hip!!*
- *Before diagnosis the frustration [of not knowing] was intolerable.*
- *Because of his illness he cannot work.*
- *He has no friends and is very lonely.*
- *The illness makes him feel different and isolated.*
- *Knowing what the problem is was very important and it helped in accepting that there was a problem.*
- *Now we know she has it and she can get treatment.*
- *It helped me and my son to have the diagnosis.*
- *My husband and daughter don't really accept that it is an illness.*
- *Family life has deteriorated since diagnosis as it is extremely difficult to manage for families and professionals.*
- *It does help to give the symptoms a label and to know it is a recognised condition, however it does not help with the day to day coping.*
- *It has helped me in that I can look for information to increase my understanding.*
- *Knowing has given us the opportunity to fight the illness.*
- *Now that we know we can react in a more appropriate way and be more patient and understanding.*
- *It helps to understand so as not to draw attention to time spent washing, also to encourage and not criticise.*
- *Without an effective treatment regime we have simply been trying to survive every day for the last 10 years.*
- *It helps to know what the problem is and that has helped to understand it but it has not helped to cope with it.*
- *We [sufferer/carer] now work together to achieve goals.*
- *Relationship with siblings has suffered.*
- *It helped when therapy was available but now it has ceased life is a struggle.*
- *Just knowing what OCD was did not really help. It was only after CBT started that there was any noticeable improvement.*

15. Does the person with OCD demonstrate any special skills or traits, such as thoroughness and order, that can be used in everyday life and work to advantage?

Yes	47	56.63%
No	35	42.17%

If Yes, do they actually use these skills?

Yes	29	61.67%
No	13	27.66%

15.1 An example of special skills is probably best explained by reference to the following small advertisement seen in a national publication:

*“SORT IT! Obsessive compulsive organises files, archives, libraries.
Business or personal, computer or paper.”*

In this instance enquiries revealed that the advertiser does not suffer from OCD but says he uses it as a joke. It is assumed that this may be to attract/mislead potential clients, however, it does indicate a special skill that can be attributed to the condition.

15.2 Many of the skills/traits given by respondents are characteristics of OCD, such as checking, attention to detail and order, perfectionism etc. It is probable, perhaps due to pride in ones children or partner that skills attributed to the sufferer are done so over enthusiastically.

15.3 Depending on the severity of the OCD and the effect on the quality of life of sufferers and carers, then, where the OCD is mild, the skill or trait may be used to advantage. An example is where a senior manager employed a member of staff who appeared to have a mild form of OCD to undertake work requiring thoroughness, patience and sorting and analytical skills. This arrangement was satisfactory to both manager and employee. (It should be noted that the OCD became apparent after employment commenced and was not the reason for employing the person.)

15.4 The following is a selection of comments received.

- *Organises and carries out laundry.*
- *Sorting things in to order.*
- *Perfectionism and order given as skills but acknowledged this to be detrimental.*
- *She refuses to work as she is scared people may notice the OCD.*
- *Having OCD has made my son very kind and understanding towards people.*
- *She has a remarkable ability to remember and to know instinctively how things worked.*
- *He has an impressive ability with writing and memory for detail.*
- *Everything he does is meticulous – it just takes a lifetime to achieve anything.*
- *He is extremely sensitive towards others and he uses this to be a wonderful caring person.*
- *To avoid “thinking” he uses computers and has become a child wonder on a PC.*
- *Very precise when making things or drawing.*
- *Has a keen brain and empathic personality, but development is blocked by OCD and he takes refuge in alcohol and soft drugs.*
- *She is very thorough and efficient in the tasks which she herself has decided to be involved in.*
- *A good organiser and has excellent interpersonal skills.*
- *The damned OCD prevents him using his many talents.*
- *Very organised and tidy, this may or may not have anything to do with OCD.*
- *Hygiene in food preparation.*
- *An excellent time keeper and very routine orientated.*
- *The skill, “order”, is only used when it suits her.*
- *He is unable to work due to the OCD and therefore unable to use the skills.*
- *Creative, practical and caring.*
- *Traits tend to be destructive and destroying to the sufferer.*
- *Uses the excuse that traits are skills necessary for his trade.*

16. Was the carer or family instrumental in getting a diagnosis?

(e.g. did the carer or a family member first recognise that the person had OCD or needed some medical advice or was it the person with OCD that made the first move to seek advice?)

It was the carer or family member	59	71.08%
It was the person with OCD	29	34.94%

- 16.1 Some respondents give both carer/family and sufferer as the person instrumental in getting a diagnosis. Where the sufferer is a child it is almost always the carer/family who were instrumental. Some respondents reported both the carer and sufferer as instrumental and in some instances no answer is given thus leading to a discrepancy in the figures. However, almost three quarters of respondents report that it was the carer which indicates that carers have observed a problem and have taken action. Many carers report that only persistent visits and complaints to GPs resulted in appropriate investigation and final diagnosis confirming the diagnosis of the carer. There is some concern about the ability and time taken by doctors to make a diagnosis (see paragraphs 14.3 and 14.4).
- 16.2 Well over half of sufferers have been diagnosed by carers and more than one-third were diagnosed by the sufferers themselves.
- 16.3 This raises the question of why it takes so long for doctors to make a diagnosis. In part this could be due to delays in getting the sufferer to visit their GP, however, a number of respondents considered that the delay was the result of a lack of awareness of the condition by GPs. This is in stark contrast to the situation in France where awareness is high and a diagnosis is made soon after the patient presents and where treatment can be started within a very short time (see appendix 3 – The French Situation).
- 16.4 The following is a selection of comments received:
- *But why did the GP fail to diagnose OCD despite many visits and many very obvious symptoms?*
 - *Why is it so difficult for the medics to diagnose OCD when carers and sufferers are able to do so quite easily? What do they teach in medical school – how to keep people out of the surgery!*

PART THREE – about the cost to families and needs of families

17. Has there been/is there a cost in financial terms to you and your family from either extra costs incurred (e.g. for the costs of treatment or special items) or for lost opportunity (e.g. for loss of earnings if someone is unable to work in order to look after the person with OCD)?

Yes	56	67.47%
No	28	33.37%

If Yes, how would you rate the cost?

Minimal cost	6	10.71%
Moderate cost	26	46.43%
High cost	26	46.43%

- 17.1 Almost two-thirds of respondents report a high cost of living with someone with OCD. Many of the No's include where sufferer does not live with carer and where there usually is no cost to the carer. Almost half give the costs as moderate to high. Costs are subjective and relate to the relative wealth and income of carers/families therefore minimal, moderate and high have been used to express the rating of costs rather than use cost bands expressed in an amount of money. Some comments give the actual costs incurred.

17.2 Costs incurred range from the cost of medication and treatment to the cost of purchasing additional cleaning materials and replacing “contaminated” items such as clothing and other everyday items that are thrown away after only one use. A major high cost is in lost opportunity either from the sufferer not being able to work or the carer giving up work to look after the sufferer. Costs also include having children live with grandparents and in more extreme cases respondents report such things as frequent house moving and scrapping cars.

17.3 The following is a selection of comments received.

- *Excessive clothes washing, bed linen, extra clothes.*
- *Lack of confidence to seek appropriate employment.*
- *Had to give up work to care.*
- *Cost of treatment.*
- *Loss of earnings.*
- *No contribution by sufferer to household costs.*
- *Replacing perfectly good “contaminated” clothing.*
- *£200 a month on toiletries.*
- *Sufferer cannot work and is totally supported by parents/family.*
- *We paid to see a hypnotherapist.*
- *I have reduced the hours I work in order to care for my daughter.*
- *Sufferer has learned to cope with the condition by doing rituals [to avoid extra costs but details not given in answer]*
- *We are paying very heavily for private healthcare because the NHS are not helping – they haven’t a clue and it makes me very angry.*
- *I quit my job as my son’s reaction was very extreme whenever I left him.*
- *My wife has had two breakdowns as a result of trying to accommodate his OCD fears and is on permanent sick leave.*
- *Large debts were built up due to rituals such as throwing away new clothes worn only once and therefore “contaminated” instead of washing them and having to purchase and wear new clothes every day.*
- *There is a large cost associated with eating out and with cleaning products.*
- *£40 per week in cleaning products, £80 per week in eating out and high electricity costs for washing and drying.*
- *Many items such as clothing and furniture are purchased and thrown away for some trivial reason.*
- *Replacing perfectly good items that could not be cleaned to the satisfaction of the sufferer.*
- *It has cost about £5,000 per year for the last 8 years mostly due to unnecessary replacement of perfectly good clothes, other items and purchase of huge amounts of cleaning materials and other “contamination avoidance” things such as disposable gloves.*
- *We found it very difficult to get Disability Living Allowance as the sufferer had no physical disability.*
- *Annual cost of cleaning products £1560*
- *We have had to move 6 times in 3 years leading to massive additional mortgage debt and other costs associated with moving of approximately £18,000.*

18. How would you say that living with someone who has OCD affects the overall quality of your life?

Not at all	2	2.41%
Mildly	10	12.05%
Moderately	11	13.25%
Markedly	28	33.73%
Extremely	30	35.14%

- 18.1 Approximately 95% report a detrimental effect on the quality of life, from moderately to markedly, with all but one reporting an improvement. With less than 3% noting no effect, and most of those where the carer does not live with the sufferer, this is a clear cause for concern and where major improvements are needed.
- 18.2 The impact on the quality of life can be huge ranging from stress and physical exhaustion to mental anguish, feelings of guilt and marginalisation. More detailed research about how this affects carers and families and their quality of life will be carried out during the interviews with carers at the next stage of this survey.
- 18.3 The following is a selection of comments received which demonstrate the detrimental effect on the quality of life of carers. While many of the comments relate to individual carers, the effect is often spread to all family members. This can be further enhanced where the primary carer is a parent and is caring, in a family sense, for other family members.
- *No social life as I need to provide support, difficult to relax, stress.*
 - *Live from day to day.*
 - *Cannot think of the future.*
 - *Destroyed my confidence.*
 - *Though I was going mad.*
 - *Hoarding makes it impossible to find items and impossible to tidy house.*
 - *No longer enjoy cooking – no room in kitchen – always full of piles of washing/washing up.*
 - *Continually feel drained and exhausted.*
 - *Unable to think of my own life.*
 - *No time for myself.*
 - *Leads to depression.*
 - *Difficult to stay positive.*
 - *Extremely stressful.*
 - *It changes your life completely.*
 - *Sufferer's outbursts and despair brings on extreme stress and anxiety.*
 - *Stress contributed to contracting MS.*
 - *It is unbearable at times.*
 - *Every day I have to "counsel" my son.*
 - *He can no longer drive because of his anxious state.*
 - *I take him out every day.*
 - *Sometimes the hurt I feel for his illness is intolerable.*
 - *Very difficult to watch someone you love in complete turmoil for no apparent reason.*
 - *My mother has always had OCD so I suppose it has affected my life but I can't compare it with "normal" so I don't know how much it may have affected me.*
 - *You are tense all of the time.*
 - *The worry of what might happen to the sufferer never goes away.*
 - *You can't sleep properly as he could be up and moving about all night long.*
 - *His anxiety affects the whole of the house.*
 - *It's hard work caring for someone with OCD.*
 - *I spend so much time trying to support my daughter I plan all other activities around her but often it is impossible to fit in anything else.*
 - *The emotional strain has been very marked.*
 - *Anxiety makes a normal family life very difficult.*
 - *Isolated from social life due to the illness.*

- *We live in a rubbish tip. Leaving would not solve the problems, only make them worse and cause many others.*
- *Majority of obsessions/thoughts towards myself (mother).*
- *Watching the family thrown into turmoil was devastating.*
- *Family relationships and marriage were all affected.*
- *Patience – you need lots of it.*
- *It is hard to maintain the will to live. Is this all there is?*
- *Stress, stress and stress.*
- *Generally the things you take for granted become difficult to do.*
- *Our relationship feels like one of dependence rather than of mutual fulfilment.*
- *OCD affects all aspects of our lives.*
- *I am appalled to consider what she has suffered.*
- *Now I probably appreciate the things I have more than before my wife became ill.*
- *I have become a “go-between” with my son and other family members.*
- *Because I choose to look after my wife I have not been able to pursue my career through its normal progression.*
- *There is always tension waiting for an “episode”.*
- *Not a “carefree” enjoy life existence. It is hard work and depressing.*
- *I need help to be able to help him.*
- *Struggling with acute OCD has been an unrelenting nightmare and has affected us emotionally and psychologically.*
- *Everyday the heartache of seeing our son not having a normal life in the way his friends were.*
- *The desperate anxiety, fear and despair, the anger of feeling helpless and the feelings of guilt that I had caused my son to be like this and the loss of sleep month after month, year after year.*
- *We have to take great care about what we say and how we say things.*
- *I am concerned that my daughter’s OCD will surface away from home.*
- *Never knowing if family occasions will be able to proceed happily.*
- *Dealing with difficult and sometimes hostile individuals from Social Services.*
- *It is impossible to plan anything.*
- *I struggle to maintain a normal life but I am leading a double life – normal and abnormal.*
- *The arguments and behaviour were random and usually short lived. With treatment he works hard to remain consistent with his behaviour. Besides, the quality of life he brought to me far outweighs the problems, and no relationship comes without its’ difficulties – it is well worth it with or without OCD.*
- *I have never felt so depressed and incapable of coping.*

19. Have you or other family members received any treatment and/or care for any effects resulting from a family member having OCD? (e.g. effects could include: stress, anxiety and depression)

Yes	30	36.14%
No	50	60.24%

If Yes, how well has the treatment, care or involvement of the family helped family members?

Not at all	6	20.00%
Mildly	8	26.67%
Moderately	10	33.33%
Markedly	2	6.67%
Extremely	0	0.00%

- 19.1 Just over one-third of carers and family members have received treatment with almost two-thirds reporting that it had helped. It is not known why the majority have not received treatment although a small number report that it has been offered but not accepted. Many carers indicate a lack of awareness or willingness by GPs and social services to acknowledge or accept that carers and families may need some support or treatment.
- 19.2 Carers and families suffer from unremitting stress. The co-dependency group model referred to in paragraph 11.3 and outlining positive gains may be an appropriate treatment.
- 19.3 The following is a selection of comments received.
- *Great effects from stress on the whole family.*
 - *Younger child has developed OCD.*
 - *Suffered a nervous breakdown.*
 - *No treatment for coping with OCD in contrast to full treatment for illness induced by stress from living with someone with OCD.*
 - *I attended a parents' course which helped my sanity.*
 - *I have no time for treatment for myself.*
 - *Talking with friends was a great help but my wife did not like me talking with people we knew.*
 - *I was referred to another therapist who suggested I distance my self from the immediate problem. But after 40 years I cannot face going back to the start again.*
 - *Help was only given to the mother but nothing was offered to the rest of he family.*

20. What has helped you most as a carer/relative to cope with living with someone with OCD?

20.1 The following is a selection of comments received. They need no further explanation, however they do indicate significant shortcomings in the medical and social services and little imagination is required to determine what is needed.

- *Friends.*
- *Love from the rest of the family.*
- *Hope that it will get better.*
- *Faith in God/religion/support from church/friends.*
- *Hobby.*
- *Other activities outside of the home/away from sufferer.*
- *Discussing the problem with the sufferer.*
- *OCD charities and similar organisations.*
- *Determination to keep the family together.*
- *Family support.*
- *Personal knowledge of OCD (from work environment).*
- *Sufferer moving away.*
- *Being hard on the sufferer to help reduce the rituals.*
- *The team at the Maudsley hospital.*
- *My husband (not my son's father) who is very tolerant and supportive of my time spent with my son.*
- *A very strong family background and help from the medical profession.*
- *I have just learnt to ignore the OCD actions, because if I react to them she seems to worry more and get worse.*
- *Mutual support of spouse and family – we must help our children even though we are now old ourselves.*
- *I needed to talk and cry outside of the home, many people have listened, sympathised and some have prayed and that brings the relief and the strength to carry on living and fighting.*

- *The newsletters from OCD charities and getting involved in their activities.*
- *Taking back some control in the kitchen where my daughter's rules and rituals and contamination fears were impossible to live with.*
- *Agreeing with my husband that we need to behave as normally as possible and not be frightened.*
- *Trying to find ways of living that we can all cope with as well as the person with OCD.*
- *Sympathy with the sufferer.*
- *Support from the carers association.*
- *Trying to help other sufferers.*
- *The realisation that we were not alone and that others were going through the same thing.*
- *Simply loving him and wanting his illness not to screw up his life.*
- *Hating OCD so much!*
- *Nothing – there has been no help.*
- *When my wife is asleep and someone or something gives me a rest from her OCD.*
- *A good cry helps sometimes.*
- *Specific people involved in treatment, usually nursing staff, not psychiatrists.*
- *Sheer desperation to get through for the sake of the sufferer – who else would look after him?*
- *Apart from the treatment, my faith and help from friends, also learning together how to cope and to come up with strategies for continuous improvement.*
- *Knowing that the sufferers behaviour is due to the illness.*
- *Trying to keep a sense of humour.*
- *The joy my wife gets from achieving something is also a joy for me.*
- *Having treatment at a specialist hospital rather than at a local level where there is no provision (or understanding) for OCD.*
- *The local association for Mental Health gives amazing support to carers and families.*
- *Weekly supportive therapy sessions.*
- *The fact that my wife has been open and honest about her OCD and that we can talk about it.*
- *There is no help!*
- *The reduction in anxiety brought about by treatment has been the only real help.*
- *A sense of humour.*
- *Our own determination and strength of character: and for the services; thanks for nothing.*
- *My wife realises that even with support, she is the only one who can make a real difference to her condition.*
- *Knowing that he wasn't weird or alone in his suffering.*

21. What would you like to see done to improve the lives of carers and relatives?

21.1 This question specifically invited comments about what carers would like to see done to improve their lives and no further explanation is necessary, however, much of this is reflected in the conclusions of this report.

- *Doctors, social workers etc do not seem to understand problems that OCD can cause to carers and sufferers.*
- *Doctors must be informed about OCD.*
- *Sympathy and understanding.*
- *More resources.*
- *Support – now only available if you are suicidal.*
- *More awareness by the services.*
- *More advice.*
- *Public education and awareness.*
- *More awareness and education in the public services.*

- *Someone carers and sufferers could both talk to.*
- *More localised services.*
- *Help in the home.*
- *Local support groups for carers and relatives.*
- *Speedier access to psychiatrist and services.*
- *Attention should be given to parents/families concerns and views.*
- *Medical staff need to recognise and accept that OCD does cause severe carer/family problems.*
- *Medical staff need to realise just how distressing OCD can be for the sufferer.*
- *Breaks for the carer/family away from the sufferer.*
- *We live in France where there is a different approach to OCD and they are streets ahead of the UK.*
- *A respite in order to maintain sanity.*
- *Rapid access to systematic support for the family.*
- *Professional people who would just listen to the sufferer.*
- *I would like to see doctors take OCD seriously.*
- *All available drugs are tried to find the best for each sufferer.*
- *Behavioural therapy is given on a regular basis.*
- *CBT should be available to all.*
- *Families should be given advice on how to care and cope.*
- *If carers and relatives had access to information it would be so helpful.*
- *If the stigma of mental illness could disappear.*
- *If the professionals were more sympathetic and informed and helpful, it would help.*
- *If CBT were available more readily.*
- *More help from the professionals about how to respond to OCD behaviours.*
- *How to keep behaving normally yourself without pushing the OCD sufferer into a corner.*
- *More understanding of mental health issues which are still misunderstood and carry an element of stigma.*
- *Mass education on special TV channels about different types of OCD and the suffering it causes.*
- *A support group specifically for hoarders.*
- *Professionals who know what they are doing.*
- *Support in the community.*
- *A telephone support line for carers and sufferers.*
- *More awareness of the different “flavours” of OCD.*
- *Help for parents with OCD children, especially within schools who usually do not understand the condition.*
- *More local help – at your medical centre.*
- *More easily available information especially for children.*
- *Local family support groups.*
- *People to listen to me and help me.*
- *Answers to the questions – what caused the problem and what is needed to overcome it?*
- *A co-ordinated treatment regime involving all parties and not just excluding or blaming carers.*
- *Mentoring and social support.*
- *Doing something other than to condemn or threaten.*
- *It is no use telling people they will always have OCD and they just have to learn to live with it.*
- *More publicity to enable the general public to see that OCD isn’t another name for madness.*
- *It would be wonderful if more people were prepared to “come out” about OCD.*
- *Recognition of the fact that carers suffer.*
- *Reversal of the “Thatcherite” policies that destroyed mental health services.*
- *Sacking of all incompetent GPs.*

- *More needs to be done to include carers in the treatment and treatment strategies.*
- *Carers need more help with finding time to themselves to relax.*
- *Councillors can be a good way of finding someone detached to talk to but they are not as accessible as they should be.*
- *A glimmer of hope.*
- *If OCD was accepted as an illness and sufferers knew there would be no stigma attached we might find life more easy.*
- *Financial help with the extra costs.*
- *Recognition. If the sufferer can't get any consideration, what hope is there for the carer/partner?*
- *There's nothing that would help other than my wife getting better.*
- *Practical help from a care team and social service provider that work together.*
- *Find a cure.*
- *Restoration of and proper investment in mental health services.*

Appendix 1. Survey response analysis

1. The carer survey questionnaire was mailed with a regular OCD Action newsletter mailing to all OCD Action members. It was also posted on several OCD organisations websites and bulletin boards.

Number sent out by mail	1200
Number of responses	83 (including electronic responses)
Response percentage	6.92 %
Electronic responses	11 ¹

¹OCD Action members were given the opportunity to respond by conventional mail or e-mail. SBC e-mailing recipients were given the opportunity of e-mailing or printing and conventional mailing. It is not always possible to determine the source (OCDA or SCB) of returns therefore the response percentage figure is distorted, however, from the initial OCDA mailing before the SCB e-mailing a return percentage of more than 5.5% was received.

2. No information is available in respect of the split in the OCD Action members between sufferers and carers. The survey was targeted at carers only and it is not known how many carers received the questionnaire therefore the true response percentage will be higher than the figure above.
3. It is probable that a greater return would have resulted if a reply paid envelope had been included but lack of resources prevented this.
4. A further electronic mailing went out via the Serving (mental health) Carers Better (SCB) e-mail newsletter at the end of the data input period as this was a good opportunity to increase the sample size and to cooperate with other mental health charities. However, the findings of this report are made using the data from the original questionnaire returns. Further returns from the SCB mailing will be analysed at a later date and a revised report made.
5. It is not known how many there are on the SCB mailing list, nor is it known what proportion are OCD carers, therefore it will not be possible to calculate a response rate.

Appendix 2. Methodology

1. The project will be carried out in three stages:

1.2 Stage 1. Carers workshop

The workshop entitled “*The Reality of Living with an OCD Sufferer*” was held at the OCD Action conference, November 2003, Birmingham, UK. It outlined the concerns of carers and families including; Support for sufferers and Coping for relatives and carers. The findings formed the basis for the carers survey.

1.3 Stage 2. Carers survey

The carers survey is the subject of this report.

1.4 Stage 3. Individual carer interviews

A number of interviews with individual carers will be carried out. They will be in a conversational style where the carer will be encouraged to talk about their case. Questions based on matters of concern as determined and influenced by the findings of the carers survey will be introduced to obtain greater, in depth views and information. Finally, a quality of life analysis will be carried out based on the Dartmouth College project 1995.

2. Literature review

2.1 A literature review was undertaken. The literature gives the effect and nature of the effects of OCD on family members, e.g.; depression etc, but it does not give the extent and depth of sufferings, nor did it reflect the UK situation. Nor did it give the feelings expressed by carers/family which is the intention of this study. The key objectives of this study are to give a clear indication on the effect on family members and on family life, also of the financial costs to families/carers.

2.2 The literature indicated the nature of the effects on carers/families but not the extent and not the UK situation.

2.3 The following is a list of works studied:

Calvorcoressi L et al, (1999). Family accommodation of obsessive-compulsive symptoms: instrument development and assessment of family behavior. *The Journal of nervous and mental disease.* 1999 Oct., Vol 187 (10), pp636-42.

Cooper. M. (1995). *Health & Social Work, Vol 20, No 4 1995*

Chakrabarti S, Kulhara P, Verma SK (1993). The pattern of burden in families of neurotic patients. *Social psychiatry and psychiatric epidemiology.* 1993 Aug., Vol 28 (4), pp 172-7.

Friel, J et al. (1984), Subby R. (19870). *Co-dependency and the search for identity.* Pompano Beach, FL: Health Communications

- Kaplan, H., & Sadcock, B. (1992).** *Synopsis of psychiatry, behavioural sciences, clinical psychiatry*. Baltimore: Williams & Wilkins.
- Koran LM. (2000).** Quality of life in obsessive-compulsive disorder. *The Psychiatric clinics of North America*. 2000 Sept., Vol 23 (3) pp 509-17.
- Livingstone et al. (1990).** Family function and treatment in obsessive-compulsive disorder. In M. Henike, L. Baer, & W. Minchiello (Eds.), *Obsessive-compulsive disorders: Theory and management* (pp. 325-330). Littleton, MA: Year Book Medical.
- Marks, I.M. (1987).** *Fears, phobias and rituals*. New York: Oxford University Press.
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Appendix 3. The French situation

- i. Although not part of this study the following sections are included for interest and as a comparison between the French approach to OCD and to relate an experience of French hospitals.
- 3.1 **Troubles Obsessionnels Compulsifs (Obsessive-Compulsive disorder)**
 - 3.1.1 The following information was given by a doctor (the French equivalent of a GP in the UK). It outlines the provision for recognition and treatment of OCD in France.
 - 3.1.2 Troubles Obsessionnels Compulsifs, or Obsessive-Compulsive disorder (OCD) In English, is probably as prevalent in France as it is in the U.K. There are self help groups for sufferers and carers, as in the U.K., dealing specifically with OCD, however, an internet search ¹ suggests that they are not as prevalent or as well known as in the U.K. with many GPs being unaware of them. The opinion of the doctor is because the condition appears to be universally recognised and generally better accepted and treated, self help groups are not needed as much as they are in the U.K.
 - 3.1.3 The doctor is confident that any G.P. in France would recognise the symptoms, and if treatment was judged to be necessary, it would begin immediately. The condition has been called TOC (OCD) for about 10 years, but had been treated for many years before without being given a special name. An awareness of the problem exists in schools (primary schools), lycees (secondary schools), universities and even the maternelles (play schools) for the very young. OCD is as well known in France as perhaps something like chicken pox is in the U.K. There are many magazine and newspaper articles in health columns and mentions on television about OCD. This is not to say it is promoted more than other ailments, but it is widely recognised by both doctors and the general public.
 - 3.1.4 Depending on the seriousness of the symptoms, an appointment with the visiting psychiatrist even in a small French country town might mean a delay of 2-3 weeks before treatment could commence, however it is possible to go to a major town for immediate treatment at the discretion of the doctor.
 - 3.1.5 All families with problems are supported in France. There is nothing specifically laid on for OCD sufferers. There are special schools, holiday centres, and visiting carers, ² and this support is the same as would be offered to, for example, a family with a hyper-active child or any family where a family member has OCD. No special financial assistance is available to sufferers and carers of people with OCD, but the umbrella that covers all family problems covers OCD and it is not given a special status.

3.1.6 There is a general awareness in France of OCD and it is given the same attention as any other health problem, with the same possibility of support from the state. Because of the greater awareness of the symptoms there is probably no greater reluctance to discuss OCD than any other illness. The doctor admits that there can always be a reluctance to admit that there is something "wrong", but doesn't believe the word "stigma" can apply to OCD.

¹ An internet search using the Google and Yahoo search engines was carried out.

² Visiting carers are thought to be the equivalent to social services support workers in the UK.

3.2 **Another French experience**

3.2.1 The following is an example of the seemingly greater awareness of OCD amongst professionals outside of medicine.

3.2.2 It was when we were living in France that my daughters' teacher actually alerted me to my daughters' excessive hand washing and suggested I contact a child clinical psychologist. It [OCD and the signs and symptoms] crept up slowly and I had not realised how serious it was and didn't know of OCD. She was then assessed and had 8 sessions of CBT with a bilingual clinical psychologist. After about six months the symptoms cleared up to a great extent. My daughter was 7 at the time and I see some re-occurrence in other forms lately since we have returned to the UK, maybe due to the change but at the moment she uses the tools she learnt and I feel we were very fortunate to get such treatment so early.

3.3 **A French Hospital**

i. The following records an experience of a patient in a French hospital and although not part of this study the reader may wish to draw their own conclusions. It is taken from the book "Deep France" by Celia Brayfield: Pan Books, London 2004.

3.3.1 The Clinique Sokorri had a special door for casualties arriving by ambulance, but it had no ER [A&E Dept.]. Nor did it have any of the things I would have expected to find in a London A&E department: no crammed waiting area, no drunks, no nutters, no dead people lying abandoned, no frazzled and guilty nurses, no warning notices about violence to NHS staff and no medical tourists, unless I counted as one.

3.3.2 A nurse appeared to assess me as soon as I arrived. Then she found me a wheelchair, and I was wheeled straight into the waiting area for the orthopaedic consultant. Dr Suleiman sent me down the corridor for an X-ray, which took about twenty minutes including the developing time, then showed me my shattered

fibula and the chipped tibia, and said “You could go home, but I’d prefer to keep you in hospital for a few days”. He was expecting me to protest. I was expecting him to do what an NHS doctor would have been forced to do – everything possible to keep me out of hospital.

- 3.3.3 The room upstairs was a spotless two-bed ward in which there was already one patient. Some friends arrived bringing me night clothes, my wash-bag and a couple of books. “Thank God this happened to you in France!” they said.
- 3.3.4 I passed a quiet weekend, except for the nurses, who just pampered me. In fact, I hadn’t felt quite so pestered to need something since the last time I stayed in a five-star hotel in Marrakesh. “How are you this morning? Did you sleep well? Because if you didn’t we can give you something. You must ask us. And have you got any pain? No, please, you must tell us if it’s still hurting. No, really, we can give you stronger pain killers, just ring the bell. Let me show you how the bell works . . .” They also explained every procedure very carefully, making sure that I’d understood in spite of my flawed French.
- 3.3.5 The room lacked those tidemarks of grime that a London hospital room seems to get within months of being built. The whole building, which fairly glowed with cleanliness, was over thirty years old, and all its equipment, some of which was far from new, seemed dusted and polished daily. “It’s so *clean*,” marvelled Andrew when he came to visit.
- 3.3.6 None of the staff ever seemed stressed, either, nor did they have the sad, guilty air that I’d so often seen in British hospitals, on people who knew they weren’t going to be able to treat their patients as they wished but couldn’t do anything about it. The only experience of rudeness I had while I was there was from the English “advisers” working for my insurers. Remembering the few but traumatic visits to hospital I’d had, I realised that to be ill or injured in Britain now often means feeling frightened, defensive and mistrustful, knowing that you will have a fight on your hands just for basic necessities.
- 3.3.7 Then there was the hospital food. It was very simple, always fresh, and delicious. Four meals a day, four courses with a little plastic glass of wine at lunch and dinner. On Sunday, we had duck *à l’orange*. The portions were, by French standards, ample. One day I wrote down the menus. Breakfast was fresh bread with butter and jam. Lunch was melon or soup, followed by chicken or hamburger with gravy, potatoes, *petit pois* and carrots with lardoons, then green salad, cream cheese and bread and cassis and lemon sorbet. At tea time, they offered me a yoghurt or fruit. Dinner always started with alphabet soup, then it was fish pie and broccoli with two poached pears for dessert.

3.3.8 By the time it was Monday, and I was lying on a trolley feeling floaty with a pre-med injection with the operating theatre lights in my eyes, trying to summon up enough vocabulary to respond to the nurse's questions about allergies and earlier operations. I really didn't feel too bad.

Appendix 4. An OCD experience

i This appendix is not part of the study but is included here to give an indication to any reader not familiar with OCD of what it is like to have OCD and to help understand why sufferers act in the way they do. It is not a medical definition as it is based on observation and comments from sufferers.

4.1 Someone with OCD may suffer from obsessions or compulsions or both. Obsessions are unwanted intrusive thoughts which repeatedly enters the person's mind and compulsions which are repetitive behaviours or mental acts that the person is driven to perform. Compulsions can involve physical acts such as repeatedly checking that a door is locked or mental acts such as continually repeating a certain phrase in the mind. According to the World Health Organisation, up to 10% of the population have OCD in some form and at different levels of severity.

4.2 Contamination is a common obsession. Want to know what it is like? On your way home buy some honey and dip the fingers of both hands in it and without cheating (no licking or wiping it off) go home, unlock the door, go in and wash your hands. Simple: but not if you have OCD. You wash your hands because they have been contaminated – but so has everything you have touched, your keys, the inside of your pocket or handbag and everything inside, the door handle, the washbasin tap and the soap. You wash your hands and they are clean, but then you have to clean the tap because you touched it before you washed your hands. But because you have touched the tap your hands have been re-contaminated so you wash them again. Then you wash the soap, but because you have touched the soap your hands have been re-contaminated so you wash them again; then the keys, then the hands, door handle – hands; door lock - hands, pocket/handbag - hands; things in the pocket - hands, and so it goes on and on and on. The “decontamination” process can take hours and it has to be done in a special way otherwise the whole sequence has to start all over again.

4.3 Then there can be intrusive thoughts. These can be about anything including doing harm to people. They involve extensive rituals or avoidance behaviour to try to be rid of the thoughts and to prevent them from actually happening. It is important to stress that the thoughts are never turned into actions by people with OCD. Sufferers develop various routines to stop these thoughts which can take hours to complete and exclude them from doing anything else during this time.

- 4.4 Then there is the checking. We all sometimes can't remember if we have locked the door or turned the gas off, but for someone with OCD this can be a major compulsion occurring every day and involves going back home many times to check even if the journey is a long one. It can take hours and will make you late for work etc or miss it altogether. Sometimes drivers will repeatedly retrace whole journeys just to make sure that they have not run over a pedestrian they saw when approaching but could not see in their rear view mirror when they have passed.
- 4.5 It isn't hard to imagine how OCD can destroy the persons' life. With the time it takes to perform rituals and the intrusive thoughts that can be like a waking nightmare there is little time left for the normal every day things in life and even that is dominated by the OCD. It is also hard on the families of people with OCD. Over three quarters of carers and family members get involved in the rituals and have to change their lifestyles considerably to accommodate them and then watch helplessly as their loved one suffers continually from this most horrible and destructive condition.
- 4.6 The impact on the quality of carers lives can be huge ranging from unremitting stress and physical exhaustion to mental anguish, feelings of guilt and marginalisation. There can be high costs involved; for example, from purchasing large quantities of cleaning materials and replacing "contaminated" items such as clothing and other everyday items that are thrown away after only one use. Some carers have had to give up work to care for the person with OCD. It is often an unremitting task without respite and with little if any time for the carers' own life. Holidays can be impossible due to the demands of rituals and compulsions. Often carers need help to cope with the situation and can find themselves in the doctors' surgery. Another source of help are self help groups available in some areas which can be of great value in helping to cope, mutual support and to share experiences with others in a similar situation.
- 4.7 OCD is a lifelong condition but it can be treated and managed, *so there is hope and together we can conquer this damned OCD.*