

# Strategic Plan

# 2009-2012

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For a society where OCD is better understood and diagnosed quickly, where appropriate treatment options are open and accessible, where support and information are readily available and where nobody feels ashamed to ask for help — it's time to act

# OCD Action Strategic Plan 2009 - 2012

#### Introduction

- 1. This Strategic Plan sets out OCD Action's vision and the core activities that the Charity plans to undertake from April 2009 to March 2012. Its purpose is to help the Trustees and the Director plan ahead and ensure that the targets and objectives are clear each year, so that they are confident that all the operational activities work towards achieving the Charity's vision.
- 2. This three year plan has been developed by OCD Action's Trustees and staff, with the valued input of the Charity's volunteers and of some of the beneficiaries of the services provided. It has been written for all of the OCD Action team and for all supporters who have an interest in seeing the organisation succeed.

# **OCD Action's Vision and Principles**

- 3. OCD Action is a national charity that provides support and information to anybody affected by Obsessive Compulsive Disorder (OCD). It also works to raise awareness of the disorder amongst the public and frontline healthcare workers. Formed by a group of volunteers and leading professionals in 1994, the charity is recognised as both a strong voice for people with OCD and a vital source of help.
- 4. OCD Action's vision is of a society where OCD is better understood and diagnosed quickly, where appropriate treatment options are open and accessible, where support and information are readily available and where nobody feels ashamed to ask for help.
- 5. OCD Action's Principles guide all activities in every area of operation and they include:
  - a. Always asking, 'How does this activity benefit people affected by OCD?'

    The Charity exists for people affected by OCD, to help, advise and secure
    a 'better deal' for them, so this question must always be asked when any
    important decision is made.
  - b. Ensuring that people affected by OCD are involved in OCD Action's decision making and in its work. By involving people affected by OCD in all the areas of operation, it is easier to ensure that their unique needs are met.
  - c. Preserving integrity and independence in OCD Action's policy positions.

    OCD Action will always act independently, so that it can maintain its credibility externally and be free from any agenda other than its own.
  - d. Ensuring that the public positions and priorities that are adopted are well informed and defensible. Many of the issues that OCD Action deals with are complicated and, in some cases, there may be differing views amongst healthcare professionals, carers and sufferers. OCD Action believes in the principle of informed patient choice and involvement in their treatment.

OCD Action will always make sure that its public positions are based on sound scientific evidence and that the Charity's case can be argued with integrity and rigour.

- e. Collaborating with, and influencing, other organisations to pursue positive programmes of action on OCD. *Undoubtedly, there are occasions when OCD Action can be more effective by working with other organisations, whether it is in providing support for sufferers or in spreading awareness of the disorder. Where it is appropriate to do so, therefore, the charity will be happy to work collaboratively.*
- f. Adopting best practice in the way that the Charity is governed and managed. All members and supporters of OCD Action have a right to expect that the Charity is efficient, professionally run, well governed and effectively managed.
- g. Ensuring that its services are accessible to all. OCD Action believes that all the services that it provides should be not only of the highest quality possible but also free to all those who would benefit from their use. The charity will ask service users to make a voluntary contribution towards its costs. OCD Action's services will be accessible to all regardless of age, race, gender, location, physical or mental impairment or cultural background.

#### **Strategic Planning**

6. OCD Action has a duty to ensure that it is able to meet its charitable objectives in the most effective way possible. In order to do this, the Charity's strategy needs to be based on a number of factors. Amongst these factors are; changes in the wider environment in which OCD Action operates, opportunities for growth that are available and the Charity's own strengths and weaknesses. By working through these various factors, OCD Action has been able to set out its operational priorities and activities.

# **Operational Priorities and Activities.**

- 7. Over the next three years, OCD Action will concentrate its management attention on the following five priority areas:
  - a. Directly supporting people affected by OCD
  - b. Raising awareness of OCD amongst healthcare professionals
  - c. Raising awareness of OCD amongst the general population
  - d. Improving services for people with OCD
  - e. Increasing OCD Action's voluntary income, in order to fund the planned expansion of the charity's services and build reserves to 3 to 4 months of future expenditure
- 8. Set out in the following pages is the overall objective for each of the priorities listed above and the specific activities and outcomes that have been agreed for each.

**Priority:** Directly Supporting People affected by OCD

**OBJECTIVE:** By 2012, OCD Action wants to ensure that it has the capacity to provide high quality direct emotional support, information and advocacy to over 180,000 people affected by OCD (10% of the estimated number of people with the disorder). This will be delivered via the internet, telephone helpline, e-mail and Support groups.

Activity	In 2009/10	In 2010/11	In 2011/12
Training & Quality	Create a new Helpline training programme and achieve professional accreditation for the service.	Instigate regular quality testing and a service evaluation programme.	
Capacity	Recruit 6 new long- term volunteers to provide support and information	Hold a volunteer recruitment drive to secure 10 new volunteers	
Befriending	Develop a new befriending service Offering callers the opportunity to talk informally to a volunteer in a similar situation	Expand befriending service recruiting new befriending volunteers nationwide	
Website	Redesign the website, giving prominence to downloadable information and online help		

Information	Review all available information	Up-date all information sheets and make available on-line	
Advocacy Service	Pilot an Advocacy Service using both peer and professional advocates	Roll out the Advocacy Service to cover 3 urban centres	Extend the Advocacy Service to cover 5 large urban areas
Working with statutory providers			Investigate opportunities and costs verses benefits of providing commissioned services to NHS authorities.
National Conference	Run a national OCD Conference attracting over 800 participants	Run a national OCD Conference and two regional workshop days.	Run a national OCD Conference and two regional workshop days
Local Groups	Work with existing local OCD Support Groups offering training and resources	Raise funds for a local group support worker to assist local groups in their work	Develop a suitable legal structure in which to manage relationships with local groups.

**Priority:** Raising awareness of OCD amongst healthcare

**OBJECTIVE:** By 2012, OCD Action will have recorded a 25% increase in awareness, amongst specific healthcare professionals, of the symptoms of OCD, best practice in managing OCD and of the services provided by OCD Action.

Activity	In 2009/10	In 2010/11	In 2011/12
Measuring the level	Undertake an	Repeat the same	Repeat the same
of awareness	awareness survey	survey as in the	survey as in the
	amongst GPs,	previous year to	previous year to
	Secondary School	measure any	measure any
	Nurses and	changes in levels of	changes in levels of
	University and	awareness.	awareness.
	College healthcare workers.		
GP Information	Develop a national	Send out a GP	Design and distribute
Pack.	GP Information Pack	Information Pack to	a follow-up
I dok.	to be distributed and	all practices	Information Pack
	downloadable via the	throughout England	I III O III a a a a a a a a a a a a a a
	OCD Action website	and Wales	
Schools and	Produce an		
Universities Pack	information and on-		
	line help pack,		
	targeted for health		
	professionals		
	working in secondary		
	schools and on		
Lia alda a sua Maralia	university campuses.		
Healthcare Media	Develop contacts within the healthcare		
Profile	media, in particular		
	GP journals		
Professional	or journals	Hold a national	
Symposium		symposium for	
' '		healthcare	
		professionals	
Training			Provide information
			to medical courses
			and offer training and
			placements to
			student doctors

**Priority:** Raising awareness of OCD amongst the general

**OBJECTIVE:** By 2012, OCD Action will have undertaken extensive efforts to increase the profile of OCD through 'un-paid for' media exposure and through national media campaigning work.

Activity	In 2009/10	In 2010/11	In 2011/12
Developing a strategic media plan and media response capacity	Agree on a national media strategy, designed to increase coverage of OCD. Train and motivate a team of media volunteers.		
Develop a Media Pack	Create a database of case studies and produce relevant press materials for background information.		
Media network	Ensure that all media contacts are contacted directly by a member of the OCD Action team, to inform them of any up-coming activity	Hold a media event to highlight OCD Action's work, linked to a relevant announcement or event e.g. conference.	
National Campaign		Undertake a national OCD Awareness campaign using all media, to promote awareness of signs and symptoms of OCD and to help tackle misconceptions and taboo	Repeat a national campaign, establishing the event as part of the awareness calendar.

**Priority:** Improving services for people with OCD

**OBJECTIVE:** By 2012, OCD Action will have worked in partnership with the Department of Health to ensure that services, in particular access to Cognitive Behavioural Therapy, are readily accessible and will have gained at least 3 commissions for the provision of services to people affected by OCD.

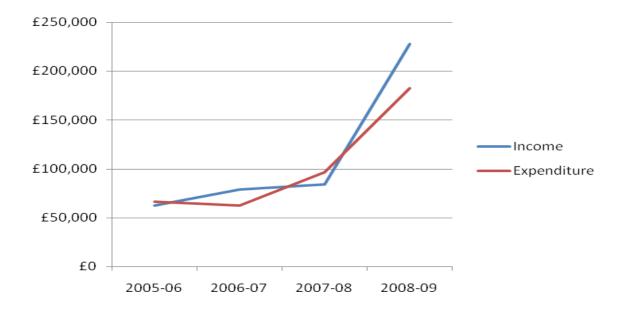
Activity	In 2009/10	In 2010/11	In 2011/12
Developing relationships with the Department of Health and coordinating lobbying work where necessary.	Develop contacts within the Department of Health so that the Charity is recognised as the primary stakeholder in relation to OCD policy.	Achieve a closer working relationship with the contacts in the Department of Health	
Understanding needs on a local basis	Through OCD's Advocacy Manager, conduct a review of the local services available to people with OCD and how this matches their needs	Continue a needs analysis to ensure that information is up to date.	Continue a needs analysis to ensure that information is up to date.

**Priority:** Increasing OCD Action's voluntary income in order to fund the planned expansion of the charity's services and build reserves to 3 to 4 months of future expenditure

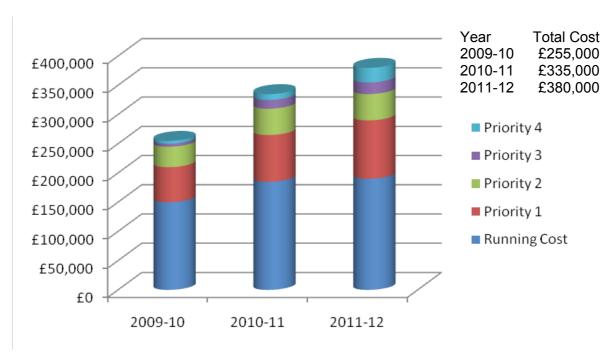
**OBJECTIVE:** Raising the income required to meet the increased expenditure is a major challenge for OCD Action and, in order to meet this challenge, the Charity needs to ensure that its fundraising activity achieves a number of objectives:

- a. Develops new sources of income and ensures diversity of income
- b. Increases the sustainability of sources of income
- c. Meets the Fundraising Codes of Practice published by the Institute of Fundraising
- d. Fits within OCD Action's agreed ethics policy

financial years and the budgeted income and expenditure for the financial year 2008-09. Income for 2008-09 is expected to be significantly higher than that of the previous year. In addition to a major corporate sponsorship, this is due to the investment received by the charity, from a charitable trust, which has enabled OCD Action to recruit a Director. Although his role is to take executive charge of the charity, he has a specific remit to develop and expand fundraising and the operational services.



10. In order for OCD Action to undertake the activities listed above, the Charity's income and expenditure will need to continue to grow over the next three years. Costs can be broken down into two groups - the regular running costs and special project costs. The graph below shows how the Charity's total expenditure is likely to grow year by year. Each column shows the total expenditure for the year and how this is made up of running costs and the costs of activity in each priority area.



11. The schedule below sets out the activity which will be undertaken to meet these objectives.

Activity	In 2009/10	In 2010/11	In 2011/12
Developing new sources of income	Establish and manage a Major Donor Fundraising Committee  Increase opportunities to participate in fundraising events  Develop and instigate a legacy donation programme.	Enter the market for commissioned service provision  Bring in new individual donors, through marketing activity	Establish a national awareness week and work in partnership with a major company as 'Charity of the Year'
Increasing the sustainability of sources of income	Establish a member & donor communication programme  Produce affective supporter material	Create a donor space on OCD Action's website  Hold regular up-date events for donors	
Meeting best practice in fundraising	Apply for membership of the Fundraising Standards Board		
Fitting within an agreed ethics policy	Create an ethical fundraising policy, to be agreed by Trustees.	Establish an ethics Sub-Committee to oversee the ethical implications of fundraising activity	

# **Using the Internet**

- 12. At the end of November 2008, OCD Action is set to launch its new website at www.ocdaction.org.uk. This website is dynamic and will grow and develop along with the Charity. Throughout the period covered by this Strategic Plan, the website has three main objectives. These are:
  - a. To disseminate clear and concise information regarding OCD, treatment options and sources of help.
    - Website users must be able to access information quickly and easily and download material as needed. All OCD Actions materials, such as help sheets and the Newsletter, will be available on-line.
  - b. To act as a safe meeting place for people affected by OCD to share ideas, concerns and make contact with each other, creating an on-line community.
    - The website will continue to provide a Discussion Board and ensure that this is well moderated and promoted. A Membership section will be created to enable members to up-date details and customise sections of the site.
  - c. To showcase OCD Action activity and encourage users to get involved.
    - The website will act as OCD Action's 'shop window'; to show all the activity that it is undertaking and make sure that people are up to date with the Charity's progress. The website will encourage involvement in on-line discussions, fundraising and volunteering.
- 13. OCD Action's website gives the Charity the opportunity to spread its message to a worldwide audience and provide support and information at a fraction of the cost of hard copy materials. However, information will always be available in this form, on request, for those people unable to access our website.

#### **About OCD**

- 14. Obsessive Compulsive Disorder (OCD) is the name given to a condition in which people experience repetitive and upsetting thoughts and/or behaviors. OCD has two main features: obsessions and compulsions.
- Obsessions are involuntary thoughts, images or impulses. Common obsessions include, but are not limited to, fears about dirt, germs and contamination; fears of acting out violent or aggressive thoughts or impulses; unreasonable fears of harming others, especially loved ones; abhorrent, blasphemous or sexual thoughts; inordinate concern with order, arrangement or symmetry; inability to discard useless or worn out possessions; and fears that things are not safe, (e.g. household appliances). The main features of obsessions are that they are automatic, frequent, upsetting or distressing, and difficult to control or get rid of.
- Just as with obsessions, there are many types of compulsions. It is common for people to carry out a compulsion in order to reduce the anxiety they feel from an obsession. Common compulsions include observable actions such as excessive washing and cleaning, checking, repeatedly touching, counting, arranging and ordering, hoarding, ritualistic behaviors that lessen the chances of provoking an obsession.
- 17. Compulsions can also be mental rituals that are not observable. These include

repeating words or phrases, counting, or saying a prayer. The main features of compulsions are they are repetitive and stereotyped actions that the person feels forced to perform. People can have compulsions without having obsessional thoughts but, very often, these two occur together. Carrying out a compulsion reduces the person's anxiety and makes the urge to perform the compulsion again stronger each time.

- 18. People with OCD often adopt avoidance behaviour, that is they avoid situations that will induce anxiety and force them to carry out compulsions. For example, a person may avoid touching a door handle as to do so would lead them to think that they are contaminated and force them to undergo lengthy decontamination rituals.
- 19. Almost everybody experiences the type of thoughts that people with OCD have (e.g. wanting to double-check the front door or the gas). However, most people are able to dismiss these thoughts.
- 20. People with OCD cannot ignore unpleasant thoughts and pay undue attention to them. This means that the thoughts become more frequent and distressing and, over time, they can affect all areas of a person's life, often their job and their family and social life.
- 21. It is important to remember that severity of OCD differs markedly between people but each person's distress is very real. People with OCD are not 'mad' or dangerous and do not carry out their unpleasant thoughts. Most people with OCD know that their thoughts are excessive or irrational but the anxiety they feel makes the thoughts difficult to ignore.
- 22. OCD is much more common than was previously thought. Prevalence estimates suggest that between 1-2 per cent of the UK population has OCD. One reason why the prevalence of OCD has been underestimated in the past is that people with OCD are often afraid to seek help. They worry that other people will think they are mad, and often do not know that their disorder is a recognised condition with effective treatments. Young people also suffer from OCD. In fact, many adults with OCD had symptoms in childhood.

#### The Need for our work

- 23. Despite the number of people affected and the debilitating nature of the disorder, reports have shown that there is an average delay of 17 years between the onset of OCD and treatment being received. This is 17 years of pointless misery and isolation brought about by a disorder that can, in many cases, by successfully managed.
- 24. There are many reasons why people with OCD delay seeking medical help. These include a fear that they will be committed to secure mental health institutions, a fear of the stigma associated with mental health disorders or a simple belief that no one can help them.
- 25. Once a person with OCD decides to seek medical help, receiving an appropriate diagnosis, and accessing therapy can take an average of 18 months.
- 26. OCD Action's services are designed to support people before, during and after the treatment process whilst the charity's awareness work aims to reduce the unnecessary delay by raising awareness amongst healthcare professionals and giving a strong and clear message to the public that OCD is nothing to be ashamed of, is not uncommon and is treatable.
- 27. Last year OCD Action coped with almost 10,000 requests for support and information. We are already seeing demand for our services grow as our profile increases and we now predict that in 2009/10 our capacity will need to increase by at least 100%.
- 28. As well as the need to provide additional support and information, 2009/10 will also see an increased need for OCD Action to ensure that the views of people affected by OCD are incorporated into the government's key initiatives and policies that are due to be drawn up in the coming year. In this way, the Charity can not only change an individual's life but also effect change on a national level.

#### **Trustees & Patrons**

29. OCD Action's trustees have responsibility for the governance of the charity, setting our strategy and ensuring that we meet our objectives. Our Trustee team comprises of medical experts, people with OCD, charity professionals and carers.

Trustees as of 2009:

Daniel Nabarro – Chair Isobel Heyman – Vice Chair Robert Eddison Naomi Fineberg Martyn Hall India Haylor Peter Jennings Colin Putney Cliff Snelling David Veale

30. As well as a trustee team, the charity also has a number of patrons. Patrons play a role in representing the charity and have over the years provided substantial help to OCD Action.

Patrons as of 2009: Prof. Kevin Gournay CBE

Prof. Stuart Montgomery

**David Prever** 

Prof. Paul Salkovskis

Dr Frank Tallis

Hon Simon Windsor-Clive The Earl of Woolton

# **Acknowledgement**

31. OCD Action's trustees and staff would like to acknowledge the help and support of all those who have contributed to this strategic plan.

#### **Contact Details**

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