



SOARS BECOMES MDMD

Following a lively discussion at the SOARS AGM in October 2015 we embarked on a consultation phase to canvas supporter opinions on broadening our objectives beyond “Old Age” and possibly selecting a new name avoiding the word “suicide”. The result was a new set of objectives, agreed by all but two respondents, and a name change to **“My Death, My Decision”** which was first choice of over half respondents, and either first or second choice for 80% of respondents. The process ensures that the Executive Council can be confident that they reflect the views of the majority of their supporters. Over the next few months we will be re-designing our website to reflect the new name.

Although the new objectives enables MDMD to campaign for those who are not “old” but who rationally wish for a medically assisted suicide, we recognise that the vast majority of those for whom this is a sensible option will be elderly. In addition, we have made no change in our aim that this should be possible without requiring any form of terminal diagnosis. Instead we focus on perceived quality of life, and the likely future quality of life.

DR ELIZABETH WILSON

It is with great regret that we have to report that Libby Wilson, FATE (Friends at the End) founder and for many years its convenor, died peacefully on 29th March. Libby was to have given a talk on “30 years as a right-to-die activist” at our April meeting. An obituary written by FATE convenor Sheila Duffy was published in the Guardian and is available here:

<http://www.theguardian.com/society/2016/apr/12/libby-wilson-obituary>

BRISTOL MUSEUM EXHIBITIONS ON DEATH AND ASSISTED DYING

Between October last year and March Bristol Museum and Art Gallery hosted two unique exhibitions, giving people an insight into many issues relating to death and dying in many cultures. The *Death: Is it your right to choose?* exhibition featured a reconstruction of the Dignitas room in Switzerland where people go for legal medically assisted suicide. The exhibitions were very popular and did much to promote a more open discussion of the issues. Both exhibitions included video clips from an interview with Phil Cheatle (MDMD Coordinator). Several other events were organised around the exhibition including a hugely popular public debate (many people had to be turned away). Speakers included Sylvan Luley (Dignitas Director), Lesley Close (Dignity in Dying Patron), an excellent case for the medical opposition from Katherine Sleeman (Clinical Lecturer in Palliative care), and Dr. John Troyer (Director, Centre for Death and Society, University of Bath). The audio is available here:

<https://www.youtube.com/watch?v=LWTO40DuD0Y&t=0h21m00s>



FATE/SOARS/MDMD MEETING IN LONDON, APRIL 9TH

The meeting opened with the news that, following the extensive consultation and voting with members, SOARS will change its name to My Death My Decision. Hasty replanning was necessary for the main part of the meeting. When Libby explained that she would not be able to speak, Michael Irwin kindly volunteered to speak instead. Unfortunately a bad gastric illness prevented him being there on the day. Instead Liz Nichols, Colin Brewer and Hugh Wynne gave short impromptu tributes to Libby and shared their memories of working with her. Many thanks to them. We then took the opportunity to have a general discussion about MDMD which raised many interesting issues about advanced decisions, our future direction, and more.

SIMON BINNER DOCUMENTARY

Many of you will have seen the moving BBC2 documentary about Simon Binner who ended his life at LifeCircle in Basle last October. Simon suffered from rapidly advancing MND which left a sociable, successful businessman aged 57, paralysed and unable to communicate. Although he himself firmly wanted to end his life in Switzerland, and had made the necessary arrangements, his situation was complicated by the fact that his wife disagreed. He delayed until life was utterly intolerable for him – far longer than he would have chosen. Eventually, after a failed suicide attempt, his wife assisted him to make the journey to Basle. This moving story illustrates how every case is different. It also highlighted the difference between the compassionate, professional, approach of Dr Erika Preisig at Lifecircle, and the approach of medical professionals in this country who were unable to engage in a rational discussion of the assisted suicide option. A particularly telling quote from Simon – which he had to write on a notepad as by that stage he could no longer speak: “GP & Consultant and Hospice → They're persuading me to stay”

In contrast, Dr. Preisig had earlier explained “You only have to listen to people. ... He's not a child. He knows what he wants to do, and it is his life. He has been taking responsibility for his life many many years and he's a strong minded person and now at the end of life that he gets weaker, he is still strong minded but people tend to treat as if they were children.”

The documentary was instigated by Michael Irwin. But despite his best efforts there was no mention of SOARS, nor credit to Michael in the programme. Despite this, Michael should be well pleased with his part in bringing about a 90 minute prime time documentary on assisted dying.

MDMD TALKS - BIRMINGHAM HUMANISTS

Recently Phil Cheatle was invited to give a talk to the Birmingham Humanists on behalf of MDMD, titled “End of Life Decisions and Assisted Dying”. Phil is happy to consider other speaking invitations if you know groups in your area who would be interested to host a similar talk.

DIE-ALOGUE GROUPS

Die-alogue groups are local groups of MDMD supporters who get together every few months to discuss assisted dying related issues, exchange views and information, and help the MDMD campaign in whatever way they are able. Currently there are groups in Brighton, North London, South London, Bristol, Cambridge and possibilities of groups in Norwich, Midlands and Devon. If you are interested in joining an existing group or forming a die-alogue group in your area, please get in touch.



MEMBERSHIP SECRETARY

MDMD is in need of someone to manage our membership records, and mailing process. Reasonable IT skills and attention to detail are required – spreadsheets, word processing, using websites... But you don't need to be a real geek! This is a vital function within MDMD – especially as we grow our membership. Any volunteers?

MDMD CAMPAIGNERS

We are creating a list of MDMD supporters who are prepared to help us keep the views of MDMD in the public eye. Activities include writing letters to newspapers and magazines; commenting on website articles etc. We will use this email list to publicise opportunities to make comments or respond to news stories, and to share our successes. If you would like to actively contribute to MDMD's objectives in this way, please email: mail@soars.org.uk.

ADVANCE DECISIONS

A major concern of MDMD is the poor take up of Advance Decisions. These are vital legally binding documents which enable you to refuse specific types of medical treatment, under conditions you specify, if you are no longer able to communicate your decision at the time. In Devon MDMD supporter Debby Henderson has been very active in working with hospitals, GPs and paramedics to promote ADs. She has arranged AD writing workshops led by Celia Kitzinger and Sue Wilkinson who are leading AD experts. The most recent was in April. Which leads to...

7th ANNUAL MDMD LECTURE

The next FATE/MDMD meeting will be held on Saturday 29th October 2016 2pm at Conway Hall, 25 Red Lion Square, WC1 when Celia Kitzinger and Sue Wilkinson will give the 7th Annual MDMD lecture provisionally titled "*Making Advanced Decisions and Keeping them Up to Date*". This will be followed by the MDMD AGM.

QUOTES

"When you see poor people, poor in the sense of having some wretched disease, pleading for their lives to be brought to an end ... It's difficult to think that they don't deserve to have that right."

[Sir David Attenborough Daily Mail 18th November 2015](#)

"I might go to Dignitas, if I was in enough pain and suffering and I was causing a lot of disruption and pain to everybody around me. I don't know if I could be bothered getting on a plane and going to Switzerland. I'm very Irish about that. Can we not do this kind of thing at home? I would have thought it is a basic human right, but it is bound around by religious considerations"

[Sir Terry Wogan who died 1st Feb 2016](#)

"Make them see sense"

[Joan Cheatle, Phil's mother, October 2013](#)

(Said in response to his explanation of how doctors couldn't help her to die as she wished. After enduring a further 2 years of very poor quality of life with advancing dementia, Joan died peacefully on 19th December 2015. Her quote is a personal inspiration to her son, now MDMD Coordinator.)

You can contact us by email to: mail@soars.org.uk