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# SOCIAL MEDIA & MENTAL HEALTH ADVOCACY BRINGING PATIENT STORIES TO LIFE



## +Why

you should be thinking about digital...

## +What

the opportunities for digital might be for patient advocacy

## +How

to get started...



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# WHY?

# Digital Advocacy



# WHY?

Digital is turning advocacy as we know it and understand it on its head

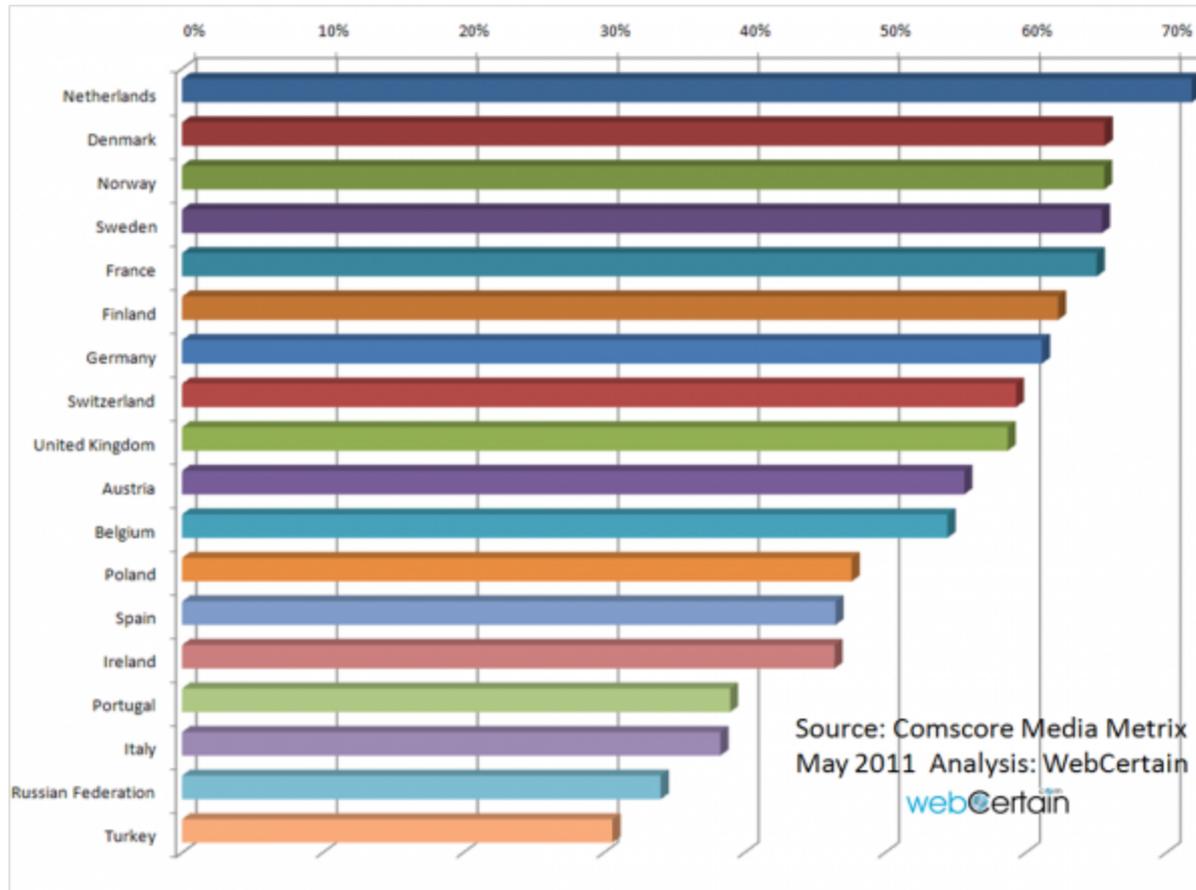
‘There won’t be a significant event in the future that won’t involve public participation... Social media (is) the sociological equivalent of climate change.’

Retired Admiral Thad Allen



# ACROSS EUROPE: TRENDING UP

## + Most active populations online...

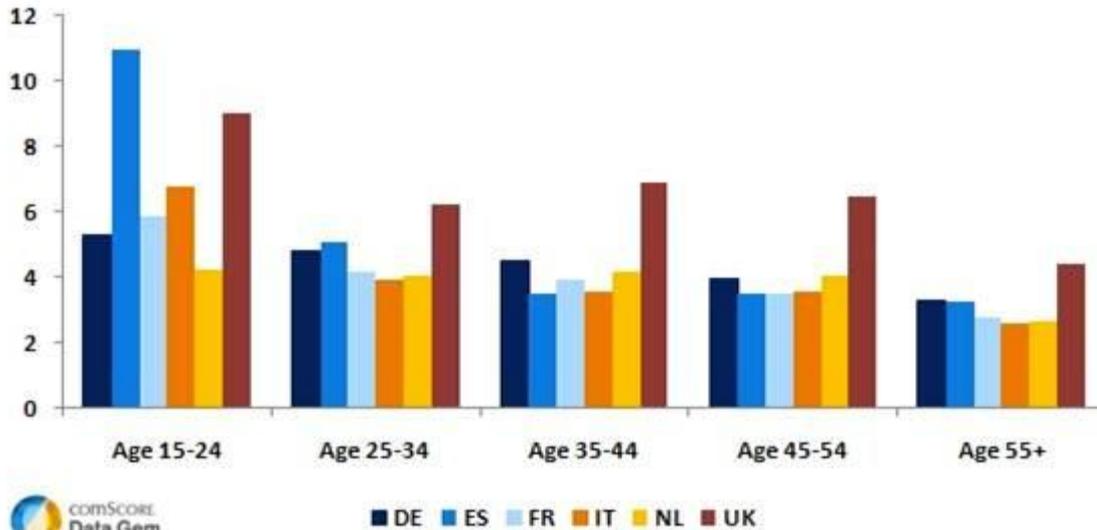


# ACROSS EUROPE: TRENDING UP

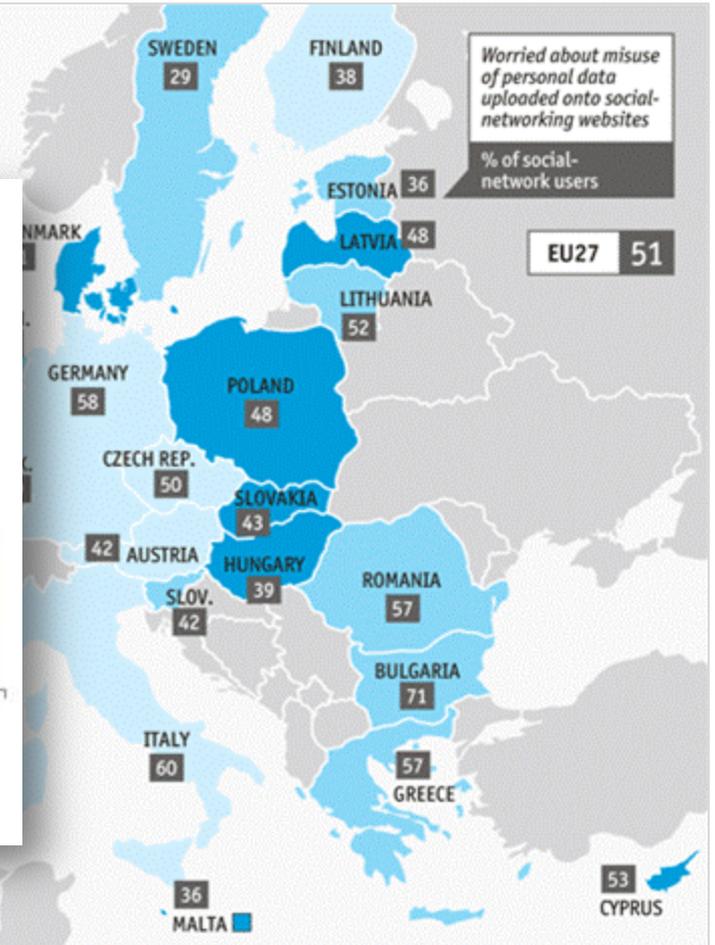


**Average Hours spent on Social Networking per Visitor across Europe**

Source: comScore Media Metrix, December 2010



Source: Eurobarometer



## Majority of our daily media interactions are screen based



On average we spend **4.4 hours** of our leisure time in front of screens each day

Base: Base: All Device Interactions - PC/Laptop (3817); Smartphone (6057); Tablet (542); TV (3592). Q. Which of the following did you use? Q. What else did you use at the same time? Note: Respondents were asked to consider printed hard copies of Newspaper and Magazine.

# WHY?

Patient advocacy in an increasingly changed world

- + **INCREASED POLITICISATION OF 'LIFE'**
- + **DECLINING TRUST IN TRADITIONAL VOICES OF INFLUENCE**
- + **NEW INFLUENCERS EMPOWERED THROUGH TECHNOLOGY**
- + **'OUTSOURCING' OF GOVERNMENT POLICY**
- + **TRANSFORMING MEDIA ECOSYSTEM**
- + **CHANGING EXPECTATIONS: TRANSPARENCY**
- + **CHANGING BEHAVIOURS: MOBILIZATION & DIALOGUE**

# WHY?

Patient advocacy in an increasingly changed world

- + INCREASINGLY, A FIRST POINT FOR HEALTH INFORMATION**
- + INCREASINGLY, A CHANNEL TO DISCOVER COMMUNITIES OF SHARED INTEREST – OTHER PATIENTS & CAREGIVERS**
- + INCREASINGLY AN OPTION TO DISCOVER ALTERNATIVES / NEW TREATMENTS**

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# WHAT?

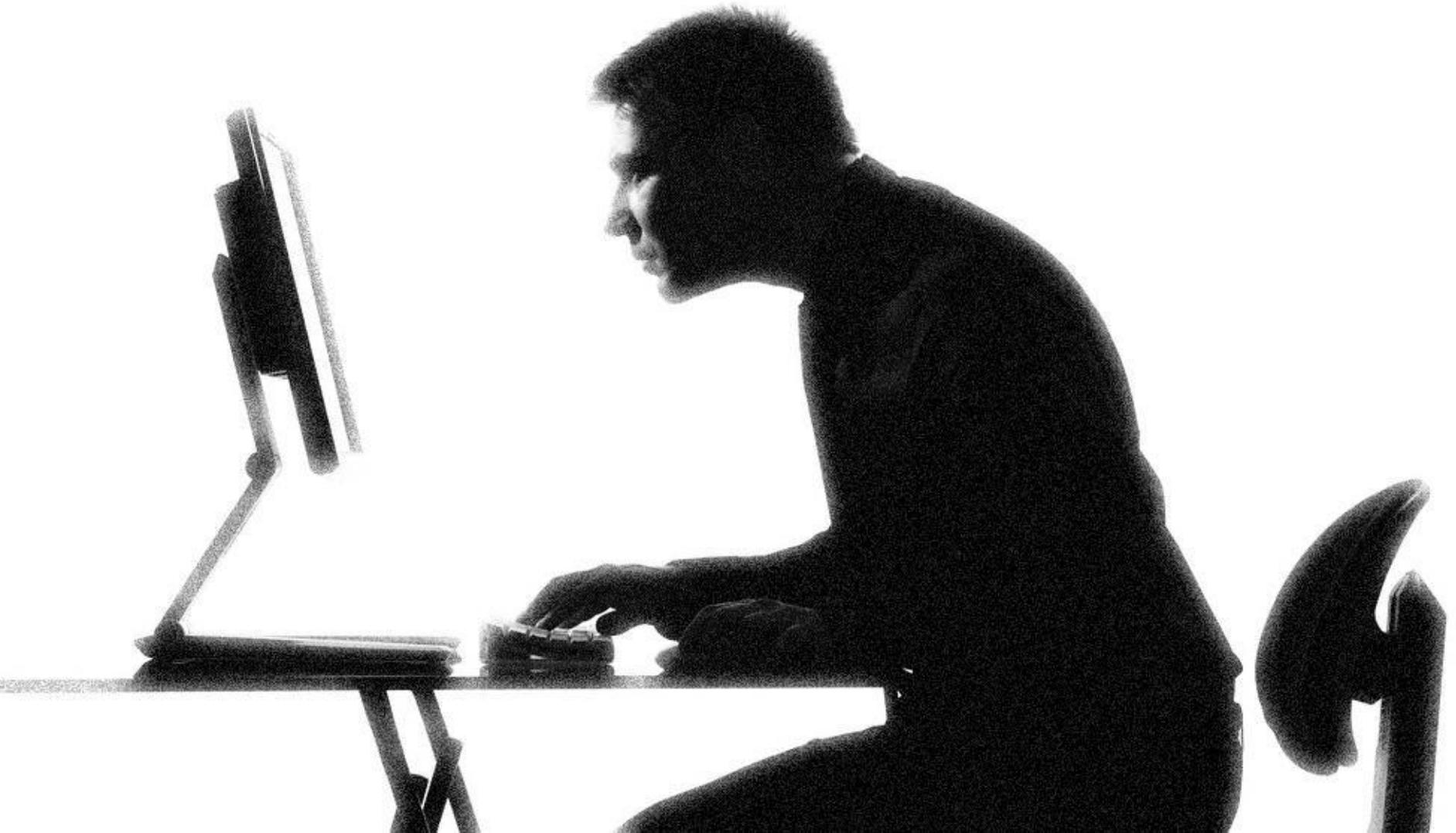
# is the real opportunity



# WE ALL HAVE NETWORKS...



+ People are “lean forward”



# THE OPPORTUNITY

For Patient Advocacy

14

**Educate**

on issues and solutions

**Connect**

voices, ideas, regions,  
data

**Collaborate**

through consultation &  
dialogue

**Motivate**

by connecting hearts &  
minds / celebrating  
actions

**Mobilize**

disconnected  
communities of shared  
interest - advocates

**Activate**

through measurable,  
efficient calls-to-action



# THE OPPORTUNITY

- + **Share useful information**
- + **Tell stories & amplify stories of others**
- + **Comment on other blogs or platforms**
- + **Link to articles & credible sources**
- + **“Newsjack”**
- + **Cross-pollinate**

# THE OPPORTUNITY

Critical Success Factors

- + **Identify solutions not only problems**
- + **Embrace collaboration**
- + **Hearts and minds**
- + **Individual and mass**
- + **Responsiveness**
- + **Transparency**

# PATIENT ADVOCACY 2.0

In Action



## Scott's Diabetes

"My struggles, my successes, and everything in between"

TAMING THE TIGER ATC RECORDS BLOGS I READ

HOME > 2011 ROCHE SOCIAL MEDIA SUMMIT > ROCHE AND RELATIONSHIPS

2011 Roche Social Media Summit We're Just Beginning - 2011 Roche Social Media Summit

Search

### Roche and Relationships

by SCOTT K. JOHNSON on JUNE 23, 2011 - 3 COMMENTS

One of my favorite people to visit with is **Bennet** from **Your Diabetes May Vary**. Two of his four kids live with type 1 diabetes, and he lives with type 2 diabetes. He gets it. He's brilliantly smart, is passionate about **diabetes** advocacy, and is not afraid to call bullshit when he sees it.

He said something to me earlier today that has stuck with me through most of the day. He said that one of the biggest things **Roche** gives us is something I know I didn't fully appreciate; the opportunity to get to know each other better.

He didn't mean **Roche** and the attendees, although that is valuable too. What he meant was US getting to know US better.

We have something very special in the **Diabetes** Online Community. We have an environment full of love, support, encouragement, empowerment, and inspiration. It starts with the common bond of **diabetes**, is actively nurtured by the open and honest sharing we all do online, and is amplified by getting to know each other better.

Great things, such as **Kim's "You Can Do This"** project, and **Sara & George's "Best of the Betes Blogs"** project (as just a couple examples), come from the relationships we build during events like this.

Thank you **Roche**.

Like 10 people like this. Be the first to...

SCOTT K. JOHNSON

Diagnosed with type 1 diabetes in April of 1980, I recognize the incredible mental struggle of living with diabetes.

[| About](#) | [Contact](#) | [Hire](#) | [Disclosure](#)

SCOTT ON TWITTER >

RT @woodonwheels: Congrats Naomi! RT @naomikingery: The Diabetic Diva® is now a registered trademark!!! | more... | 6 hours ago

@datangeL82 Makes total sense to me. I get crabby & short with my family too when that happens. Glad to hear you're feeling better. | more... | 16 hours ago

FAVORITE QUOTES

"If the rest of the world understood the inability to actually control this disease, I think we would get a little more empathy and little less blame thrown our way."

- George Simm

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# HOW? to get started



# HOW

- + Creating a Facebook page, a Twitter account or a blog takes a matter of seconds...
- + Your challenge is to use each of these tools in the way that helps you effectively advocate...

TOPICS

Stephen Hawking

Jwovv

# Start by answering a few questions...

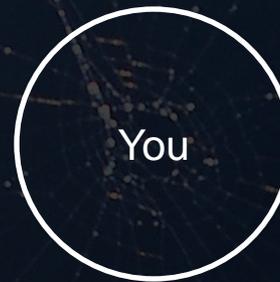
- + **Why am I doing this?**
- + **What is my end goal?**
- + **What's my action plan?**
  - Resources. Content. Etc.
- + **Where do social media tools fit?**
  - Which tools will best help me achieve my goal?
    - Tell a story, amplify news, start a conversation...
  - Where are the people I am trying to reach & mobilise?



# BEST PRACTICES

## + **Keep it simple & stick to the basics:**

- Walk before you run
- Keep it human
- Make it visual
- Post regularly
- Link / reach out to others
- Amplify
- Aggregate and curate
- Respond



# DIGITAL ADVOCACY

The Right Approach

***“I see our website as our home base, our blog as our podium, and Twitter, YouTube, Flickr and LinkedIn as our megaphone.”***

WWF Global Social Media Manager

The screenshot shows the WWF website with a navigation menu at the top: Home, Take Action, Your Organisation, Blogs & Stories, News & Media, Time to Talk, and Young People. A search bar is located in the top right corner. The main banner features the text "time to change let's end mental health discrimination" and "Don't know how to talk about mental health? Read our tips..." with an illustration of two men talking. Below the banner is a news section titled "Top employers make pledge on World Mental Health Day" with a "Full story" link. To the right, there is a "Need support?" section with a "Help for you" button, a "Follow us:" section with social media icons for Facebook, Twitter, and YouTube, and an "Email sign-up" button. At the bottom right, there is a "Take action:" section with buttons for "Make a pledge", "Send an e-card", "Upcoming events", and "Become a Champion".

# Critical Success Factors: Social





# Advocacy in Action

26

The screenshot shows a Twitter interface with a tweet by Alastair Campbell (@campbellclaret) and two replies. The tweet discusses a blog post by @IndiaKnight about depression stigma. The replies are from Andy Carling (@quarsan) and Insp Michael Brown (@MentalHealthCop), both supporting the original tweet's message.

Home Connect Discover Me

Alastair Campbell  
@campbellclaret

blog - @IndiaKnight so wrong to say 'no stigma to depression' and 'everybody gets depressed' - Time to Change  
[alastaircampbell.org](http://alastaircampbell.org)

66 RETWEETS 12 FAVORITES

9:19 AM - 9 Oct 12 · Embed this Tweet

+ Twitter as amplifier & driver of engagement...  
+ Example of timely response: newsjacking!

Andy Carling @quarsan  
@campbellclaret you're right on both counts

Insp Michael Brown @MentalHealthCop  
@campbellclaret @indiaknight Spot on - from my perspective, I see the stigma connected to depression and mental illness every day.

Internet | Protected Mode: On 125%

# Advocacy in Action: Mobilization

## partnersformentalhealth

Français / Login

HOME

JOIN ACT GIVE / LEARN SHARE NEWS

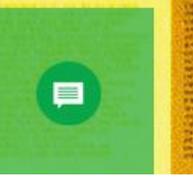


view all

Share Your Story



MARY (TORONTO)



**partnersformentalhealth**  
Françoise / Login

HOME JOIN ACT GIVE / LEARN SHARE NEWS

## act

6 things you can do right now.

- TAKE THE 'NOT MYSELF TODAY' PLEDGE**  
Show your support for improving mental health in Canada by taking the 'Not Myself Today' pledge. [PLEDGE](#)
- DONATE**  
Your donation helps us put in place the campaigns and actions that will improve mental health in Canada, from changing attitudes and behaviours, to ensuring that people get the help they need, when they need it. [GIVE NOW](#)
- VOLUNTEER**  
Movements begin and grow with people like you. We'd love to have your time, your voice, your brilliant organizational skills – anything you're happy to give us. [GET INVOLVED](#)
- SPREAD THE WORD**  
We need as many people on board as possible to affect real, lasting change. Tell your friends, your family, even your co-workers about the cause – anyone who's listening. That's how we'll make a difference faster. [f](#) [t](#)
- REACH OUT**  
Support someone you know who has a mental health issue by listening openly, offering reassurance, providing information or encouraging them to get help. [FIND RESOURCES](#)
- INFLUENCE POLICY**  
Here's your chance to use your people power. Contact your elected officials to help influence policy that will improve the mental health system. [LEARN MORE](#)

THANKS TO OUR SPONSORS:

**NOT MYSELF TODAY**

**Home**  
**Pledge** Sign the pledge of support for mental health  
**Share** Join the conversation by sharing your story  
**Act** Things you can do right now  
**Issue** Learn about the issues & why change is needed

**MAP YOUR MOOD**

**FRANÇAIS**

**TAKE THE PLEDGE**

Mental health can no longer be ignored. We are all affected. We are all touched by it. That's why we are pledging our support to improve mental health in Canada.

0 30,000  
28,811

28,811 have taken the pledge. Help us get to 30,000!

**TAKE THE PLEDGE**

**SHARE YOUR STORY**

**MAP YOUR MOOD**

**FIND HELP**

Thanks to our sponsors: Scotiabank

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The screenshot shows the Mind website's 'Latest' blog page. At the top, there is a navigation bar with links for Home, How we can help you, Our campaigns, Latest, Shop, Get involved, About Mind, and Work with us. The Mind logo is on the left, and the Mind infoline number (0300 123 3393) and email (info@mind.org.uk) are on the right. A search bar and a basket summary (0 items = £0.00) are also visible. The main content area features a large image of a woman's face with the word 'Latest' overlaid. Below this, there is a breadcrumb trail: Mind home > Latest > Mind blog. The 'Latest' section includes links to News, Mind blog, About the Mind blog, Mind's media office, and Mind Media Awards. The main article is titled 'Blogging about mental health issues' and discusses the weekly publication of blog posts on various mental health topics. It includes a section for 'A-Z of mental health' and 'Your stories'. A sidebar on the right contains a 'Blogroll' with links to various mental health resources like BBC Ouch!, Beating worry, and Community Care: Mad world. The date '10 October 2012' and the title 'A Fish's (viscious) Circle' are visible at the bottom of the main content area.

Log-in Mind Cymru

**mind**  
For better mental health

Mind infoline 0300 123 3393  
info@mind.org.uk

Your basket: 0 items = £0.00 [Go to checkout](#)

Search site:

Home | How we can help you | Our campaigns | **Latest** | Shop | Get involved | About Mind | Work with us

**Latest**

Find us in your area  
Enter postcode  [Q](#)

Help us by donating  
Make a donation online now [▶](#)

Mind home > Latest > Mind blog

**Latest**

- ▶ News
- ▶ **Mind blog**
  - ▶ About the Mind blog
- ▶ Mind's media office
- ▶ Mind Media Awards

A-Z of mental health  
Information and advice on a huge range of topics

Your stories  
Read about how other people have coped.

**BLOG**

**Blogging about mental health issues**

Each week we publish blog posts on a whole range of topics, relating in some way to mental health — written by Mind staff, service users and health and policy professionals. Some blog posts may not reflect official Mind policy.

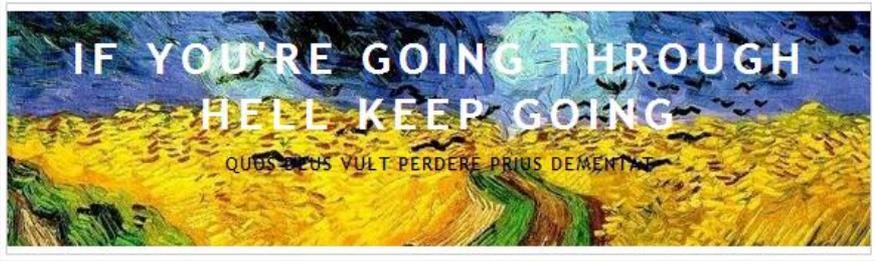
We welcome comments and questions on our posts, but have a few [ground rules](#) to keep the site welcoming and interesting to every body. The first rule is the most important: be respectful of other commenters and bloggers.

10 October 2012  
**A Fish's (viscious) Circle**

**Blogroll**

- ▶ BBC Ouch!
- ▶ Beating worry
- ▶ Community Care: Mad world
- ▶ Confessions of a serial insomniac
- ▶ Counselling Directory blog
- ▶ Frontier Psychiatrist
- ▶ The Guardian: mental health section
- ▶ Into the system...
- ▶ Mental Political Parent

Delen 1 Meer ▾ Volgende blog»

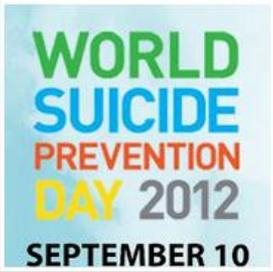


MEDS I HAVE TAKEN

- Meds I have taken-What I did for love

MONDAY, SEPTEMBER 10, 2012

### World Suicide Prevention Day, September 10, 2012



Today is World Suicide Prevention Day. Almost every site I have seen have places to call if you are feeling suicidal, and lots of history and statistics of suicide. Some bloggers are adamant that suicide can be prevented. Some aren't. A few sites, eager to show that the blogger has a very good education, spew out facts from Durkheim, and go into 21st century stats.

Here's the honest truth. Most suicides can be prevented. Most suicidal behavior, if taken over that hump when a person is suicidal, leads to the person being glad the next day they are still alive. I've met several people in real life who are grateful their attempt(s) failed. I've met people who as they were swallowing pills ended up calling 911 because they changed their mind.

Then I've met people, including myself, who were upset they failed. They can't figure out what went wrong, every detail was planned to the Nth degree, and something caused it to go wrong.

YOU LIKE ME! YOU REALLY LIKE ME!!



TOP TEN MENTAL HEALTH BLOGS



SUBSCRIBE TO

- Posts ▾
- All Comments ▾

PATIENT BLOGS I REALLY LIKE

- A Bit Mad Ted
- Before You Take That Pill
- Beyond Meds
- Bipolar Recovery

PATIENT BLOGS I REALLY LIKE

- A Bit Mad Ted
- Before You Take That Pill
- Beyond Meds
- Bipolar Recovery
- Caught In My Bipolar Burble
- Chronic Impending Disaster
- Civil Rights in Psychiatric Hospitals
- Coming Out Crazy
- Coming Out of the Trees
- Daily Living in a Manic-Depressive World
- Demons Within Me
- Different Thoughts
- Fighting The Darkness
- Finding Optimism
- Furious Seasons
- Hope For The Flowers
- In Pieces
- In Pursuit of Happiness
- Involuntary Transformation
- Journey of an uppity intellectual activist crip
- JustAna

ON



## World Mental Health Day Blog Party, October 10, 2012

By JOHN M. GROHOL, PSY.D.

Welcome to the World Mental Health Day Blog Party for 2012. This is the official blog listing where we will be updating every blogger who blogs for World Mental Health Day.

Remember, if you want to blog for the day and help us increase awareness around mental health issues and treatment, please [see the instructions here](#). (Write us at [blogparty at psychcentral.com](mailto:blogparty@psychcentral.com) to let us know of your published blog entry!)

Your blog post can be about anything related to mental or emotional health, or its treatment. You can tell your story about how you first learned about your condition, and what kinds of challenges you faced to get treatment for it.

### Blogs That Have Contributed to World Mental Health Day, 2012

Most recent entries are listed first. This list will be continuously updated throughout the day on October 10, 2012, so check back often!



#### Mental Health Day

About

Grab the Badge: How This Works

#### Categories

General

#### Archives

- October 2012
- September 2012
- October 2011
- September 2011

### Results for #WMHD12

Tweets Top / All / People you follow

**WHO @WHO** 10 Oct  
Today is World Mental Health Day, @WHO is calling for an end to the stigmatization of #depression [goo.gl/9myFJ](http://goo.gl/9myFJ) #WMHD12  
Expand

**Linda @beautiful\_again** 7h  
New on Walks with Cookie | What I learned on #WMHD12 - [wp.me/s2JcQA-wmhd12](http://wp.me/s2JcQA-wmhd12) share, RT, comment :)  
[View media](#)

**Oxford Academic @OUPAcademic** 11 Oct  
The theme of World Mental Health Day is 'Depression: A Global Crisis'. [oxford.ly/ORmmSf](http://oxford.ly/ORmmSf) #WMHD12  
Expand

**Hannah Gadsby @Hannahgadsby** 10 Oct  
it's #mentalhealth week. be kind, patient and gentle. carry it over to next week too. #WMHD12  
Expand

**ABC The Drum @ABCthedrum** 10 Oct  
Being depressed is so, well, depressing - @benpobjie shares his experience for #mentalhealth week #depression #WMHD12 [bit.ly/QSPLKc](http://bit.ly/QSPLKc)  
Expand

**WHO @WHO** 10 Oct  
MT @lwaborderline: @WHO Yes 1 yr of #depression can be crippling, affects everything. Meds and counseling helping #WMHD12  
Expand

**Johnson & Johnson @JNJStories** 10 Oct  
In honor of World Mental Health Day, learn more about treatment & recovery options for patients at [choicesinrecovery.com](http://choicesinrecovery.com) @janssenUS #WMHD12  
Expand

0 Meer ▾ Volgende blog»

## KNOWLEDGE IS NECESSITY

FROM GOD TO NEURONS

MONDAY, SEPTEMBER 10, 2012

### Rerun: My Good Friend Kevin



*In honor of World Suicide Prevention Day ...*

Eight years ago, I was facilitating a DBSA support group in Princeton, NJ. In walked Kevin, exuding a goofy charm, baseball cap on backward. But there was something about his presence that indicated he was no mere goofball. The

others in the room felt it, too.

Over the weeks, I couldn't help but be impressed by the way Kevin carried himself. He would walk up to newcomers and introduce himself and start up a conversation. In the group, he was a great listener, dispensing the wisdom of a sage, leavened by a keen sense of humor.

It was amazing to observe him with people much older. At once, he was deferential, compassionate, and exuding great authority. You simply forgot you were talking to someone much younger. You simply wanted to be around him, laugh with him, seek advice from him.

He had his setbacks, his dark moments. Yet, over time - in group, over coffee, over sandwiches, hanging out - I watched him blossom. With his extraordinary people skills, the sky was the limit.

In late 2006, my marriage broke up. Kevin was the first to offer me support. He also reached out to my then-wife.



ABOUT JOHN MCMANAMY AND KNOWLEDGE IS NECESSITY



I am an award winning mental health journalist and author.

[More ...](#)

MY NEW PAPERBACK!



[Raccoons Respect My Piss But Watch O...](#)  
John McManamy  
[Best Price \\$9.95](#)



Meer ▾ Volgende blog»

## KNOWLEDGE IS NECESSITY

FROM GOD TO NEURONS

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ABOUT JOHN MCMANAMY AND KNOWLEDGE IS NECESSITY



I am an award winning mental health journalist and author.

More ...

MY NEW PAPERBACK!



[Raccoons Respect My Piss But Watch O...](#)  
John McManamy  
Best Price \$9.95

My award-winning website, now in its twelfth year, with a new look and fresh content. More than 200 articles dedicated to helping you make intelligent choices.

WELCOME

Knowledge is Necessity



FEATURED VIDEOS

NAMI San Diego County



# Advocacy in Action: Video

35

**YouTube** [Search] Browse | Upload **Brendan Hodgson** 40 + [Profile]

**John McManamy** + Subscribe 178 subscribers 141,804 video views

Featured Browse videos Search Channel

Uploads Playlists Likes Feed Comments View

**John McManamy**  
Author John McManamy explains common situations and practical solutions for those living with depression and bipolar disorder.  
mcmmanweb.com

by John McManamy

Latest Activity	Sep 16, 2012
Date Joined	Mar 27, 2008
Country	United States

**Funk Barkley and His World ...**  
84 views | 3 weeks ago

**NAMI San Diego Welcome**  
21 views | 1 month ago

**Raccoons Respect My Piss...**  
1,536 views | 5 months ago

**NAMI San Diego.mov**  
68 views | 7 months ago

**NAMI San Diego County Wal...**  
81 views | 1 year ago

**NAMI San Diego County Wal...**  
500 views | 1 year ago

# Advocacy in Action: Facebook

The image shows a screenshot of a Facebook page for a group named "Fightdepressio". The page header includes a profile picture of a red flower, the name "Fightdepressio", and the text "253 likes · 8 talking about this". Below the header, it says "Health/Wellness" and "An interactive community dedicated to supporting each other." There is an "About" section and a "Post" section with a text input field.

Two posts are highlighted with white boxes:

- Post 1:** Shared by Jamie Leggatt on 24 September. The text says "Because i could not stop my girlfriend's photo." Below the text is a black and white photo of a woman smiling, with the text "true friend" and "can see what behind the smile." The post has "Like · Comment · Share" options.
- Post 2:** Shared by Jamie Leggatt on 21 September. The text says "Shit Happens's photo." Below the text is a black background with white text: "Sometimes all you can do is not think, not wonder, not imagine, not obsess. Just breathe, and have faith that everything will work out for the best." The post has "Like · Comment · Share" options.

At the bottom right of the screenshot, the logo for "HILL+KNOWLTON STRATEGIES" is visible.

**Each of you will have your own way to communicate...**

**That reflects the time you have...**

**And if you are a creator, storyteller, sharer, commenter, mobilizer or activist...**

**Which are you?**

