Our Lives

@Onlyfluffyone Let's all find cool bed pics .. Happy bed pics… Sad bed pics… Share our beds and share our stories x
https://twitter.com/Onlyfluffyone/status/307087415288426496

@Onlyfluffyone We have to have hope… Get involved. Let people know the reality of what it's like… Life…
https://twitter.com/Onlyfluffyone/status/307053242485993472/photo/1

@lizlips Essential requirements by the side of my bed:
https://twitter.com/lizlips/status/318024607649116162/photo/1

@MarkOneinFour So you wanted a #beddingout photo from me @rgplizcrow? Here's me and a friend in bed right now.
https://twitter.com/MarkOneinFour/status/317622701839773699

@Onlyfluffyone Those who are or have been confined to your bed… Now is your time to join in and have your voice heard.
https://twitter.com/Onlyfluffyone/status/317585092744732672/photo/1

@Onlyfluffyone Some days I just need sandy toes… Being stuck in bed is bad enough without persecution for being sick.
https://twitter.com/Onlyfluffyone/status/317053720191979520/photo/1

@Peckitt Bad pain day today I think. There are days when I quite simply hate my body.

@CC_Me_AND_ME Having an invisible illness and juggling life: disability and public perception is hard…
http://beddingout.roaring-girl.co.uk/liz-crow-i-can-and-will-rely-on-adrenalin-kicking-in-enough-that-i-can-deceive-the-onlooker-beddingout-reallife/

@RGPLizCrow Love the bedlife videos [see 'Our Lives'], they make so much difference. Keep them coming.

@RGPLizCrow Sue Marsh: "Over time, us sickies and spoonies become adept at covering up, at hiding the pain"
http://diaryofabenefitscrounger.blogspot.co.uk/p/health-update.html

@RGPLizCrow Jess visits Laura, bedside friends, bedside laughs. What makes **your** bed life better?
https://twitter.com/RGPLizCrow/status/310343094837055488

@BADHofbauer As a person with an illness that causes disability I hate the way that is all I am to some people.

@soundcube Sometimes we 'invisible' feel the weight of both disability and mainstream worlds pinning us down.

@Onlyfluffyone My dream bed #NeuroME peeps what's your dream bed? Join in pictures stories and a discussion 😃
https://twitter.com/Onlyfluffyone/status/309048115250462720/photo/1

@Onlyfluffyone I don't moan much at all… But some things bug me… I'm ignoring the negative in favour of hope..
https://twitter.com/Onlyfluffyone/status/308653689483169792/photo/1

@RGPLizCrow 'Bella just takes over the second I get up." My bed by Helen. I'll show you mine if you show me yours
https://www.facebook.com/photo.php?fbid=158026671020745&l=d0e90b4690

@Onlyfluffyone If you had to spend lots of time in bed due to sickness what bed would you choose? I like this one
https://twitter.com/Onlyfluffyone/status/307216910456602624/photo/1

@RGPLizCrow I love it! Dream location for my bed-life. Think DWP would approve?
https://twitter.com/RGPLizCrow/status/307099101269467136/photo/1
@cowbird @RGPLizCrow You! Concerned about DWP approval! Methinks not!

@Onlyfluffyone: A snowy bed…. What would your dream bed be ?
http://theonlyfluffyone.wordpress.com/2013/03/25/a-snowy-bed/

@skirrid How about this one
http://www.qualitycottages.co.uk/supimages/1043/1043bed.jpg its ours! More
http://www.qualitycottages.co.uk/laugharne-studio-estuary-views-dog-1043.php

@Quinonostante @Suey2y disability activist and author of 'Diary Of A Benefit Scrounger' in a #bedlife video for #beddingout
http://diaryofabenefitscrounger.blogspot.co.uk/2013/04/liz-crow-bedding-out.html

@RGPLizCrow I've been struck by the levels of compassion which shine from these videos.

@Dannilion Watch "My Bedroom" on YouTube
https://www.youtube.com/watch?v=pk7QBqKiYMs #NeuroME#MECFS

@Dannilion My Bedroom: Because all the cool kids are doing it and to support #beddingout. Life with severe ME sucks but penguins are awesome and I'm happy.

@Dannilion Done #BeddingOut video. Uploading now. When it's sorted I'll be napping as talking and moving so much knackered me

@BurkettLou Thank you Danni for showing your room x loving the spotty duvet! And your awesome smile! Lou x
Jan O'Malley @Dannilion Good to hear your voice! ;o)

@RGPLizCrow Watching #beddingout bed-life videos (a thousand thanks for them). One thing that shines out is human beings' motivation to be active, contributing despite all.

@RGPLizCrow Sue Marsh, #beddingout with her amazing comfy pillows and her amazing warm spirit! Video
http://diaryofabenefitscrounger.blogspot.co.uk/2013/04/liz-crow-bedding-out.html

@Quinonostante "Being safe is really important, and a random jar of chillies!"

@Suey2y in a must be seen video!
http://dawnwillis.wordpress.com/2013/04/04/being-safe-is-really-important-and-a-random-jar-of-chillies-suey2y-in-a-beddingout-must-be-seen-video/

@claireOT This is me, to facilitate the #occhat about #beddingout.
https://twitter.com/claireOT/status/321720543575416832/photo/1

@lisapeacefrench @RGPLizCrow As you prepare for your #beddingout I too have
decided to share the secrets of my PTSD:
http://reallylisafrench.wordpress.com/2013/04/09/a-life-with-post-traumatic-stress-disorder/

@RGPLizCrow Helen Bryant from that hospital bed – hoping you are on the up

@TwigsTrillycake
https://twitter.com/RGPLizCrow/status/321472313965047808/photo/1

@RGPLizCrow Can't quite get comfy? Can't sleep? Me neither! Maybe this would help
https://twitter.com/RGPLizCrow/status/321442444296204289/photo/1

@allbigideas Does anyone have any other names for 'notwell' = bad day but not sick (in normal sense)?

@RGPLizCrow I've recently started talking about my bed-life… Anyone else got ideas?

@RGPLizCrow We've been asked for a more empowering term for bed bound.

@long2b Quite like 'bed dweller,' though sounds a bit like a hobbit…

@twowolves Remarkable and moving: ‘A Life With Post Traumatic Stress Disorder’ #ptsd #mentalhealth #beddingout http://beddingout.roaring-girl.co.uk/remarkable-and-moving-a-life-with-post-traumatic-stress-disorder-ptsd-mentalhealth-beddingout/

@Kitschmonkey Self portrait: my private world of #ME #CFS http://krystalgault.tumblr.com/image/47619968858

@Katharine_T Pretty much 85% of my life is spent like this. http://twitpic.com/cibtjq

@stuckinscared Life as a disabled person is filled with guilt in the face of loved ones and shame in the face of society. It is being stronger than you ever imagined you could be, knowing you did your absolute best and it still wasn't good enough.

@wildcandytuft This makes me feel so sad and isolated. I have agoraphobia and am mostly housebound. I wish the world would come to me at times.

@ambir That is why #beddingout on twitter can be so important. People can join in from their bedroom and feel included.

@wildcandytuft Yes, I'll be #BeddingIn for #BeddingOut

@WOWpetitionchat Raise public awareness to end the stigma of disability. Debunk the myths and cut through the rhetoric.

@Simplicitly As carer, I try and make sure it's not me that decides #beddingout, but probably on about 1% of days I call the shots if I can see exhaustion. But on those 1% of days when I gently suggest that today is a #beddingout day, I know I'm right if I don't meet too much resistance! I think #beddingout has made me ponder the factors influencing whether other half is in or out of bed: Illness, expectation, routine?

@butanoverture I often struggle to do everyday tasks due to low energy from hypothyroidism and lack of motivation from mental health problems. A day when I get ready and leave the house unprompted is a good day. A day spent mostly vertical is a good day.

@SquirblePip Convalescing...? It's not exactly empowering when you can't move... More importantly, is your mind free?

@LordReynolds I have three or four naps a day, after getting up at 10ish, and back to bed by eight!

@Onlyfluffyone What the world does not see of ME: http://theonlyfluffyone.wordpress.com/2013/04/05/what-the-world-does-not-see-of-me/

@Onlyfluffyone I did a YouTube for #beddingout. I'm amazed that 190 views and some great comments… but the reality I'm reduced to tears. It's my life

@CreativeCrip Great irony of @FutureGov's BenefitsCamp last year? I participated online while trapped in bed. http://thecreativecrip.wordpress.com/2012/02/06/one-life-to-live-the-irony-of-benefitscamp-2/

@Kewryta @RGPLizCrow Thanks for sharing your bed-life. Here's mine. Note title boxes to cover messy background. https://twitter.com/Kewryta/status/322361625006972928/photo/1

@CreativeCrip My life now is what it is and I am who I am. I am not lazy or a victim. I am more than my disabilities. https://twitter.com/CreativeCrip/status/322360661432750080/photo/1

@kirstymhall: Here I am. Not heroic. Not lazy. Not a victim. Just my life. https://twitter.com/kirstymhall/status/322347896475353088/photo/1

@CreativeCrip The ME/CFS Ghost @TheMECFSGhost An ill person's reality is seen as negativity by the Positivity Police! Our stories are so important.

@PenPep Resting up now. Left hospital yesterday. Here's me in my Bed. Will return! Much love to Liz x https://twitter.com/PenPep/status/322329454523342848/photo/1

@jeshyr This is my life. How I use computer: https://twitter.com/jeshyr/status/322309014677491712/photo/1

@KwillNews I want to send this to everyone who says "If you can use a computer, you can work." How many offices have this set-up?

@jeshyr Also I'm very hit and miss. Some weeks/months too sick to do productive stuff because I can't think. Other times I do though!

@bluehook The little things that make a big difference, like getting my toenails seen to. Will that be cut too? http://img.ly/u3UI

@Onlyfluffyone What I see… The reality of my world… #beddingout is helping to show and share the reality of our hidden lives. https://twitter.com/Onlyfluffyone/status/322290118599774208/photo/1

@lisapeacefrench I may not actually sleep much in my bed, but this little lady will keep me entertained! https://twitter.com/lisapeacefrench/status/322146049286365184/photo/1

@twowolves 'Disabled my arse, a great video!' @suey2y @bendygirl #WOWpetition http://www.youtube.com/watch?v=RiLuNpATiSw&feature=youtu.be&buffer_share=aecee&utm_source=buffer

@claireOT We're leaving #centerparcs. I've got permission for a late checkout so I can rest before the journey https://twitter.com/claireOT/status/322646237734121473/photo/1

@lisapeacefrench if you thought my blog about #PTSD was inspirational, you should read the replies I've had! #amazing http://reallylisafrench.wordpress.com/2013/04/09/a-life-with-post-traumatic-stress-disorder/

@CC_Me_AND_ME I blogged "Disabled My Arse!" video via

@CC_Me_AND_ME Fantastic video by a paralympian on misconceptions. http://www.youtube.com/watch?v=RiLuNpATiSw&feature=youtu.be&buffer_share=aecee&utm_source=buffer

@seniorchuffy "Emily sets the record straight" http://goanimate.com/videos/0b0WHakiGZQc/1?utm_source=twitter&uid=049r3NmG6FDA&source=goanimate.com

@seniorchuffy Confronting disabling British society: http://goanimate.com/videos/0fJ4e70VnDhE

@yourupsetsoami Why do shop assistants talk to the carer rather than the disabled person when it is the disabled person making a purchase?

@BADHofbauer This really pisses me off too. I land up doing a shouty Brit abroad way of talking to them as if they're stupid. They still don't get it though, just look as me as if to say "My God, It Talks" (then I knock something over).

@onmybiketoo Disability myths: You are in a wheelchair, therefore I need to speak to you like you can't hear or understand me.

@ATurtle05 You're in a wheelchair, therefore I need to speak to your pusher not you.

@Onlyfluffyone #beddingout is sharing the true facts and true stories of what is happening to the sick and disabled. Tomorrows list https://twitter.com/Onlyfluffyone/status/325761507889643520/photo/1

@lisapeacefrench Gave a talk on resilience yesterday. It's on my blog and shows the brighter side of my PTSD. #RPGLizCrow http://reallylisafrench.wordpress.com/2013/04/13/my-reflections-on-bedding-out/

@CC_Me_AND_ME Slept nearly all day. My life is shrunk to windows of living. Surviving. Coping.

@kohima44terry I wasn't always disabled. My tax rate was 50% when I was working for over 20 years.

@QuietNotStupid Life as a disabled person is a lifetime of guilt because without me, my family could have the chance of a 'normal' life.

@Jules_Clarke My bowel disease: when you meet someone for an hour or so, and shoot to the loo **four** times. When you see me you don't know. I call it the grudge. When 'its evil' it sounds like this: https://www.youtube.com/watch?v=3XwWIepDRp4 If i disappear suddenly, from meeting, conversation or anything it **could** be the incredible magnetism between my arse and the loo, If I'm with you and leave the room or the building unannounced, I am responding to illness, not being rude.

@katythenightowl Being one of those bed-bound, I'm so very glad that you are highlighting the problems we all face :)

@PhillipVickysda Disability is is is is is is is is is is is is is is is is is is is is is endless…

@kirstymhall I have M.E and I'm a total Pollyanna type. Of course it gets me down sometimes but my glass is still half full.

@claireOT People who say "you look so well" when they see me have no idea how much time I spend #beddingout.

@KathyOleary I know that feeling! I keep the sunnyside out as much as possible but don't show bad #beddingout days.

@Simplicitly 'You look really well' comment struck home, I hear people say it to my Mrs all the time, and we smile and agree, and it doesn't take any account of how bad the night or the day before or the hours before might have been. #beddingout made me think, so thanks.

@Cardifolderol Very true re neuroME stereotypes. My 'public' persona and smiling face confuses those who think M.E. equals negativity! They resist truth!

@RGPLizCrow My dream bedroom: wide doors to sitting/workroom, flexible space for
good/bad/inbetween days. (Note 2 self: lottery ticket).

@Spoonydoc: #beddingout Blog post "Lost life, busy bed!" Oh, and as an aside, see where Spartacus Report was written! http://loopys-rollingwiththepunches.blogspot.co.uk/2013/03/beddingdown-lost-life-busy-bed.html

@RGPLizCrow @Spoonydoc Love love love this! Spartacus Report makes this part of disability history!

@twheaterer I sometimes enjoy working with laptop in bed. The difference is I have a choice.

@RGPLizCrow Melissa’s bed “It’s the ship from which I navigate the stars, but it’s injuring my spine. It’s a complex marriage, my bed’s and mine.”

@RGPLizCrow ‘My Bed’ by Dennis Q “It’s the hub of my world almost everything important I have ever done was done here ” What is your bed?

@RGPLizCrow Gabi L: “My bed is my sanctuary. Nothing feels so bad it can’t be fixed, nothing hurts as bad, when I’m in my bed.”

@missdennisqueen My leccy bed is my couch, workstation, playspace, physio support, aid to sitting/standing, kids cuddle space. I even sleep in it sometimes. I'd love to hear others tweet about how important their bed is and why. :)

@SquirblePip Mine stores quite a few clothes, plus some books. It's also a sort of docking station for me and my phone...

@missdennisqueen For me, my bed is a crucial aid to independence and provides health benefits. My bed and time I spend in are crucial to welfare. I'm away from home at the moment, waking with whiplash injury from poor positioning. So all I really want is **my** bed **here** :)

@Barbsisi My bed is very important as spend most of the time in it or reclined on it.

@missdennisqueen When I finally get home to my superbed, I think I'll get a celebratory picture. Was big step getting hospital bed but it's super. My electric bed has been life-changing. I can now sit and stand in middle of night and mornings. No more bedsores. Bed rocks. Just think how much easier life would be if all disabled people had the equipment and support they need. Add inclusion for utopia. It could be done. But for now we continue to fight tooth and nail for our basic survival. Keep fighting. Never give up.

@Barbsisi Having a wheelchair that reclines (legs included) has helped my back and hips loads.

@BrieVandekunt Finally. Back in my own bed a long seven days later. I automatically feel safer. #blanketsasarmor #sicklife

@missdennisqueen It's so so good to be back in my electric profiling bed. Can pee at night and everything! Real rest and healing. :)

@jamg3916 My bed is my haven, a place of peace, but also a prison when I am awake in the middle of the night.

@lizlips My bed is my sanctuary and also my prison.

@criquaer I call it my "bed-cell" too! %D

@mmaher70 The bed sometimes seems like our prison, when we can't do what we wish.

@onmybiketoo Yep that’s how other half felt: bed=prison when he had a pressure sore on his back. Three months in hospital last year.

@Simplicitly For my other half, bed is a prison, but also a place we can do most 'good' through physio, cups of tea, rest and sleep. I think there are connotations of it being a 'cocoon' from which butterfly can emerge, but an enforced one!

@missdennisqueen I love my electric bed. It enables me to sit stand and position so I don't injure. My bed is clever – I bet the upgrade makes tea! Wrong beds are widespread. Isn't it stupid: wrong bed can injure us! Hotel bed is damaging me - pain roared like a bear this morning! And then there's the hours of painsomnia spent in bed in hope of sleep!

@SquirblePip Painsomnia...! That is a *brilliant* word. If it hasn't been around for ages already, you should spread it.

@theyoungjane Can you patent a word? No? Thought not, just an idea...

@LordReynolds I know that one. Only a couple of on/off naps last few nights. Got a new memory mattress which helps a bit. Reading the Ikea catalogue at 3am this morning!

@missdennisqueen Greetings fellow insomniac :) I finally got some sleep but woke with neck injury again.

@FordCarole LBC 97.3 kept me going when I was partially bedridden for 7 years in the 1980s.

@RGPLizCrow @janeysian says “I just want to be reassured I am not forgotten.” http://notprimarilyutilitarian.wordpress.com/2013/03/12/73/ #invisibleillness

@Cardifolderol: Had shower. Shower’s left me struggling to manage things I had shower for, like dressing/cooking/functioning.

@claireOT I’ve just woken up… Been asleep since taking a bath this morning and going for a nap.

@JuJuMarlow The myth I hate the most, that personal care assistance should come from family or spouse. My hubby is my partner, not my carer.

@Peckitt So here's the thing. There comes a point when your friends start “you want sex?” Or “You know about sex?” Yes I do and do again!

@FionaArt Just saw @RGPLizCrow take a sip from her bottle of water. I know what it is to drink laying down due to being scared/unable to get up.

@claireOT I’m often #beddingout on the sofa so I still feel part of the family. https://twitter.com/claireOT/status/322645903653625856/photo/1

@DanielleSheypuk#beddingout can also represent the isolation of disabled people by society from dating and sex.

@kirstymhall@RGPLizCrow talking about the meaning of her bed on #beddingout. My bed is my respite and my solace but also my enemy.

@Katharine_TPretty much 85% of my life is spent like this. http://twitpic.com/cibtjq

@tiggerbumble Living on the edge, just about making it through, is soul destroying.

@Onlyfluffyone We aren’t alone xxx