

Twitter debate around status of prior beliefs following severe brain injury

Here is some of the twitter debate around the question of the place of a person's prior values and beliefs if, following brain injury, they might be happy because they lack insight into their condition

This debate happened around the hearing concerning Paul Briggs in the Court of Protection (#COPBriggs)

The court hearing was live tweeted by Jenny Kitzinger and Celia Kitzinger from the Coma and Disorders of Consciousness Research Centre (www.cdorc.org.uk)

A record of the discussion in court and an analysis of the arguments was presented in the powerpoint: <https://cdorc.org.uk/persons-wishes/>

Scroll below to see some of the interactions from a wide range of people such as lawyers, clinicians, family members and Independent Mental Capacity Advocates.

Commentary included a mixture of

- **Personal experience** e.g. “after 5.5 years this happened [too me/my loved one]. No insight into limitations, appears happy. But former personality gone & would hate this.”
- **Assertion of their own values and beliefs** e.g. @SVPhillimore: “Agency is such an important part of what makes us human.; @katemasters67: “personal autonomy is paramount to me.”
- **Debate about the principles and practice** e.g. “Changed/different person argument should only be deployed when P [person] can communicate change”
- **Detailed discussion reflecting on their professional experience** e.g. @DerickWaderehab [neuro-rehab consultant] wrote an extended statement and @JakkiCowley [Advocate] contributed a thread discussing how she: ‘support someone to remain at home due to past wishes even though dementia left them ‘unaware’ of being at home’.

Scroll down through the following 12 pages to get a glimpse into the debate (and see the rich engagements that can be generated on twitter!).



Jenny Kitzinger @JennyKitzinger · Dec 13, 2016



If a person's said they wouldn't want life-prolonging treatment, but there's still a chance they'd recover to be happy - should you give it? twitter.com/KitzingerCelia...

Celia Kitzinger @KitzingerCelia

Still waiting for #COPBriggs judgment. Meanwhile our analysis of Trust argument on P's wishes & 'new person' theory cdoc.org.uk/persons-wishes/ twitter.com/CDOCuk/status/...



Sarah Phillimore
@SVPhillimore

[@seethrujustice](#) [@KitzingerCelia](#) their wishes must be respected. Agency is such an important part of what makes us human.

♥ 1 5:24 PM - Dec 13, 2016



[See Sarah Phillimore's other Tweets](#)



Sue Wilkinson
@sue_wilkinson



Raises key issues around prospective autonomy (as instantiated in Advance Decisions, and elsewhere). Grounded in ongoing case of #COPBriggs twitter.com/CDOCuk/status/...

Coma Research @CDOCuk

Our analysis of the role of person's wishes in best interests decision-making, based on #COPBriggs cdoc.org.uk/persons-wishes/ #mentalcapacity

♥ 3 7:40 PM - Dec 8, 2016



[See Sue Wilkinson's other Tweets](#)



Kate Masters @katemasters67 · Dec 14, 2016



Replying to [@KitzingerCelia](#) [@thomaswoodcock](#) that's what I'm saying. They've chosen what they would not accept, which equates to the life they want.



Kate Masters
@katemasters67

personal autonomy is paramount to me.

♥ 1 9:17 AM - Dec 14, 2016



[See Kate Masters's other Tweets](#)





Barbara Rich
@BarbaraRich_law



Inferred present wishes have a role in MCA best interests decisions but sometimes impossible or purely speculative to infer anything at all twitter.com/cdocuk/status/...

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OS says "uncontested" evidence Paul is now different person makes relevance of submissions about his past values+wishes unclear #COPBriggs

♡ 2 8:52 PM - Nov 30, 2016



[See Barbara Rich's other Tweets](#)



Coma Research @CDOCuk · Nov 30, 2016



OS set bar very high for 'gd' evidence of P's wishes - + then challenged them anyway on grounds that P is a different person now #COPBriggs twitter.com/CDOCuk/status/...

Coma Research @CDOCuk

OS doesn't accept convos Paul had about Nicklinson case or his mother-in-law's feeding tube are directly analogous to Paul's situation now.



Tom Woodcock
@thomaswoodcock

in years Ive been teaching the 'different person' argument students most unsympathetic.

♡ 1:48 AM - Dec 1, 2016 · Lester, PA



[See Tom Woodcock's other Tweets](#)





Jenny Kitzinger @JennyKitzinger · Nov 30, 2016



Anyone else think Official Solicitor is interpreting 'best interests' in ways which mean 'prior expressed values & beliefs' get sidelined?? twitter.com/CDOCuk/status/...

Coma Research @CDOCuk

OS set bar very high for 'gd' evidence of P's wishes - + then challenged them anyway on grounds that P is a different person now #COPBriggs twitter.com/CDOCuk/status/...



Hoary Frost

@circuserithacus

@LoomesGill @CDOCuk Changed/different person argument shld only be deployed when P can communicate change: proxy dangerous

♡ 2 4:58 AM - Dec 1, 2016



[See Hoary Frost's other Tweets](#)



Jenny Kitzinger @JennyKitzinger · Dec 3, 2016



#COPBriggs P now minimally conscious & possibility he might emerge, so maybe treating clinicians speculating re wishes of 'future person' twitter.com/circuserithacu...

Hoary Frost @circuserithacus

Replying to @JennyKitzinger

@LoomesGill @CDOCuk It's a perversion of a 'new person' argument. I'd look to equate personhood w/ consciousness.



Hoary Frost

@circuserithacus

Seems practitioners are playing fast and loose with the law and ethics of the matter. Can't invent & define future person

♡ 2:32 AM - Dec 3, 2016



[See Hoary Frost's other Tweets](#)





Life of B

@BBwinch



Intriguing argument...he could be the same but Trust seems to ignore this possibility.

twitter.com/CDOCuk/status/...

Coma Research @CDOCuk

Official Solicitor: Where there is no advance decision prior wishes can not trump everything else #COPBriggs He is a different person now

♡ 2 4:14 PM - Dec 1, 2016



See Life of B 's other Tweets



Celia Kitzinger

@KitzingerCelia



Still waiting for #COPBriggs judgment. Meanwhile our analysis of Trust argument on P's wishes & 'new person' theory cdoc.org.uk/persons-wishes/

twitter.com/CDOCuk/status/...

Coma Research @CDOCuk

We'd welcome feedback on P's wishes (past, present, future) in best interests decision-making (w ref to #COPBriggs)cdoc.org.uk/persons-wishes/

♡ 5 8:18 AM - Dec 13, 2016



See Celia Kitzinger's other Tweets





Celia Kitzinger
@KitzingerCelia



Great discussion 'new person' argument in advocacy + serious medical decisions. Thks
[@jakkicowley](#)+[@Stephenpublic17](#) cdoc.org.uk/persons-wishes/



Jacqueline @jakkicowley · 14h
I recently supported someone to remain at home due to past wishes even though dementia left them 'unaware' of being at home.

Jenny Kitzinger @JennyKitzinger
#COPBriggs What r differences in #NewPerson argument when applied to P w. dementia v. P suddenly rendered unconscious w severe brain injury? twitter.com/VickyLShepherd...

← 1 ↻ 1 ❤️ 2 ⋮



Jacqueline @jakkicowley · 14h
It could have been argued environment not relevant to P if they're not aware they're at home, but Ps past expressed wishes paramount.

← 1 ↻ 1 ❤️ 4 ⋮



Stephen Evans @Stephenpublic17 · 1h
[@jakkicowley](#) [@JennyKitzinger](#) I see diff if life = issue. Past wishes always relevant: so is q of whether P might be ok with situ once in it

← 3 ↻ 1 ❤️ ⋮



Stephen Evans @Stephenpublic17 · 1h
[@jakkicowley](#) [@JennyKitzinger](#) I don't like the "new person" argument taken to extreme i.e. why are wishes of previous person relevant at all

← 1 ↻ 1 ❤️ ⋮



Stephen Evans @Stephenpublic17 · 1h
[@jakkicowley](#) [@JennyKitzinger](#) think I see it more as P being treated as much as poss like a person with cap: inc weigh new info; change mind

← 1 ↻ 1 ❤️ ⋮



Jacqueline
@jakkicowley

[Follow](#)

♡ 1 9:11 PM - Dec 13, 2016



[See Celia Kitzinger's other Tweets](#)



Celia Kitzinger
@KitzingerCelia



Severely brain injured patients are not always happy - leading rehab expert describes wailing in distress + attempts at self-harm #COPBriggs
twitter.com/CDOCuk/status/...

Coma Research @CDOCuk

Insights from @derickwaderehab challenging assertion that its justified to overrule P's prior wishes as 'He might become happy' #COPBRiggs twitter.com/derickwadereha...

♡ 1 9:44 AM - Dec 8, 2016



[See Celia Kitzinger's other Tweets](#)





Insights from [@derickwaderehab](#) challenging assertion that its justified to overrule P's prior wishes as 'He might become happy' [#COPBRiggs](#)
twitter.com/derickwadereha...

Derick Wade @derickwaderehab

Should the 'POSSIBILITY' of a person moving from MCS into a state of 'not being distressed' overrule known past values & wishes? [#COPBRiggs](#)

Should the **possibility** of 'being happy' over-rule all other considerations? What is the evidence?

A proportion of people in the minimally conscious state do regain some cognitive function, sufficient to be considered aware but severely disabled. But many do not, and it is not possible to predict in an individual case. The likelihood of the possibility is unknown.

In as far as minimally conscious people do have awareness, it is not necessarily pleasant. One patient known to me only showed meaningful behaviour when a person known well to the patient was within earshot; the patient turned away and curled up in a foetal position strongly suggestive of fear. The pre-morbid relationship with the other person had been poor. Another patient known to me showed a very meaningful response to one topic of conversation; whenever the patient's children were mentioned or present, the patient started crying profusely. At other times the patient wailed in distress, sufficient to require morphine to alleviate the prolonged distress. Others, more aware, have also been distressed or required sedation/analgesia for pain.

For people who recover into a state of severe disability, it is true that some severely disabled may appear to be content or at least not unhappy and not in distress. However philosophically I am less certain that this can be equated with happiness. Happiness comes from a sense of achievement, achieving activities or states consistent with a person's deeper values. A person may get some pleasure from a hot bath or an amusing TV programme, but this is not itself happiness and indeed unhappy people can nonetheless enjoy basic pleasures.

It is also true that a significant proportion of people with severe disability may be very distressed, and at the extreme may need sedation or very close and constant care simply to remain safe. One recent patient known to me was nursed on an acute ward with 24 hour nursing observation because of his distress and repeated attempts at self-harm - and this is not uncommon.

I would conclude that:

♡ 4 1:43 AM - Dec 8, 2016



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Derick Wade
@derickwaderehab



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I would conclude that:

♡ 4 10:41 PM - Dec 7, 2016



[See Derick Wade's other Tweets](#)





Celia Kitzinger @KitzingerCelia · Dec 13, 2016



Shld people who would've wanted to refuse treatment have that refusal respected - even if person has chance to be happy if t'ment given?



Jenny Kitzinger @JennyKitzinger · 12h

If a person's said they wouldn't want life-prolonging treatment, but there's still a chance they'd recover to be happy - should you give it?

Celia Kitzinger @KitzingerCelia

Still waiting for #COPBriggs judgment. Meanwhile our analysis of Trust argument on P's wishes & 'new person' theory cdoc.org.uk/persons-wishes/twitter.com/CDOCuk/status/...

4 replies 8 retweets 2 likes



Tom Woodcock @thomaswoodcock



Following

@JennyKitzinger @KitzingerCelia that was my job, answer is I respected freely made choice, even in a child.

LIKE

1



9:39 AM - 13 Dec 2016

1 reply 1 retweet 1 like



Sascha Baldry @SLBaldry

does apparent absence of pain/distress=happy? What does 'happy' look like? Dif. for all IMO

1 like 9:07 AM - Dec 14, 2016



[See Sascha Baldry's other Tweets](#)





Derick Wade @derickwaderehab · Dec 7, 2016



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I would conclude that:



Karen Turner RN
@karenturner9

after 5.5 years this happened. No insight into limitations, appears happy. But former personality gone & would hate this.

♡ 1 5:52 AM - Dec 8, 2016



See Karen Turner RN's other Tweets



Coma Research
@CDOCuk



Painful if loved one loses 'former personality'-esp if former P wild refuse this. Goes to heart of Dworkin/Dresser debate #COPBriggs #ethics twitter.com/karenturner9/s...

Karen Turner RN @karenturner9

Replying to @derickwaderehab

after 5.5 years this happened. No insight into limitations, appears happy. But former personality gone & would hate this.

♡ 2 12:10 PM - Dec 8, 2016



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Lise Barry
@lawandageing



Conclusion "It is wrong to hold PB's past wishes hostage to a 'new' and 'happy' possible future self" #COPBriggs
cdoc.org.uk/persons-wishes/

♡ 3 11:17 AM - Dec 13, 2016



[See Lise Barry's other Tweets](#)



Celia Kitzinger @KitzingerCelia · Dec 1, 2016



Pleased to inspire discussions - can u let me know more?
twitter.com/katehayes20011...

Sally Hayes @sallyhayes57

Replying to @KitzingerCelia

stimulating debate in my class today !



Sally Hayes
@sallyhayes57

teaching end of life module at @AdultUWE pre reg nurse
- discussed briefly today - more tommoro in ethics
session

♡ 1 6:15 PM - Dec 1, 2016



[See Sally Hayes's other Tweets](#)



Sally Hayes @sallyhayes57 · Dec 1, 2016



Replying to @KitzingerCelia

teaching end of life module at @AdultUWE pre reg nurse -
discussed briefly today - more tommoro in ethics session



Sally Hayes
@sallyhayes57

also encouraged stds to join twitter to watch it play out !
Court of protection always feels so hidden so enjoying
watching

♡ 6:17 PM - Dec 1, 2016



[See Sally Hayes's other Tweets](#)





Sue Spencer
@kind_curious



Storify and disseminate @GdnHealthcare
twitter.com/kitzingercelia...

Celia Kitzinger @KitzingerCelia

I'm live tweeting #COPBriggs court case - gruelling & complex issues to address. Can tweeting this help inform public debate? #SocialMedia

♡ 1 2:51 PM - Nov 30, 2016



[See Sue Spencer's other Tweets](#)



Coma Research @CDOCuk · Dec 13, 2016

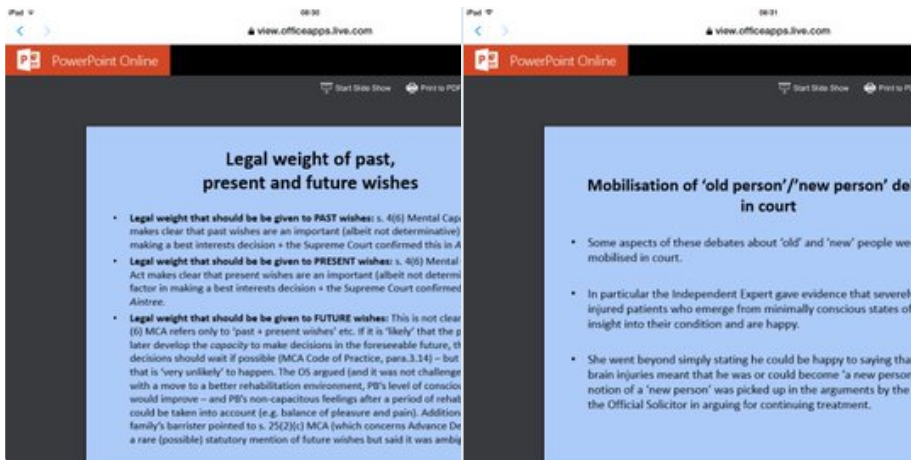


We'd welcome feedback on P's wishes (past, present, future) in best interests decision-making (w ref to #COPBriggs)
cdoc.org.uk/persons-wishes/



Dr Sarah Russell
@learnhospice

this is an excellent summary & sharing of a difficult issue. These 2 slides really hit home for me. Your info is a must read..



♡ 3 8:35 AM - Dec 13, 2016



[See Dr Sarah Russell's other Tweets](#)



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