

Correspondence with NICE re. Clinical Frailty Score

Email thread 1: emails between the National Autistic Society and NICE

From: [redacted] NR [redacted]@nas.org.uk>
Sent: 25 March 2020 11:12
To: Paul Chrisp <Paul.Chrisp@nice.org.uk>
Cc: National Institute for Health and Care Excellence (NICE) <nice@nice.org.uk>
Subject: RE: Important clarification re: rapid guideline on critical care

Hi Paul,

Thanks again for your assistance the other day. I really appreciate it.

I just wanted to make you aware of this petition, if you haven't already seen it:
https://twitter.com/Talkback_UK/status/1242150293657260034?s=20.

This isn't something we've been involved in, but we've been asked online to share. Given we have already made our position clear publicly and with you, I would like to be able to reassure people who are concerned, rather than share the petition.

If that helps with getting an autism-specific clarification that we can help promote, that would be incredible.

Kind regards,

[redacted] NR [redacted]

Head of Policy and Public Affairs

Wed 25/03/2020 12:12

From: 'paul.chrisp@nice.org.uk'
Cc: 'nice@nice.org.uk'
To: [redacted] NR [redacted]@nas.org.uk>

[redacted] NR [redacted]

I've been tied up in meetings and calls all morning. Thank you for drawing our attention to the possible consequence of applying the CFS to people with autism. That consequence was not intended. It has been agreed to amend the guideline to read:

1.1 On admission to hospital, assess all adults for frailty, irrespective of COVID 19 status.

- . Use the Clinical Frailty Scale (CFS) for frailty assessment, available from the NHS Specialised Clinical Frailty Network as part of a holistic assessment of frailty.
- . Be aware of the limitations of using the CFS tool as the sole assessment of frailty. The CFS should not be used in younger people, people with stable long term disabilities, learning disabilities, autism or cerebral palsy. An individualised assessment is recommended in all cases where the CFS is not appropriate.
- . Consider comorbidities and underlying health conditions in all cases.
- . Record the frailty assessment in the patient's medical record

This amendment will be made as soon as possible. I hope that resolves the issue. We are intending to communicate this change more widely today.

Best wishes
Paul

Dr Paul Chrisp
Director, Centre for Guidelines
National Institute for Health and Care Excellence

From: [redacted] NR [redacted]@nas.org.uk<mailto:[redacted] NR [redacted]@nas.org.uk>>
Sent: 23 March 2020 13:44
To: Paul Chrisp <Paul.Chrisp@nice.org.uk<mailto:Paul.Chrisp@nice.org.uk>>
Cc: National Institute for Health and Care Excellence (NICE)
<nice@nice.org.uk<mailto:nice@nice.org.uk>>
Subject: Important clarification re: rapid guideline on critical care

Dear Dr Chrisp,

I hope you do not mind me contacting you directly.

I am contacting you from the National Autistic Society. We have read the rapid guideline on critical care published over the weekend and are concerned about how assessments of frailty will be applied, according to the guideline, to "all adults". The list of criteria outlined in the Clinical Frailty Scale, include criteria such as help keeping finances in order, meal preparation and help with dressing. We are concerned that these criteria outline difficulties that many autistic people face - but that does not make them frail. On the current wording of the guideline, though, this assessment would be carried out. This could lead to doctors making decisions about otherwise healthy autistic people that would put them at serious risk.

We believe strongly that NICE needs to clarify the application of this guideline and make clear that an autistic person's support needs will not lead to decisions being made about their access to critical care. We also believe that it is critical that doctors and other health professionals get clear guidance about how to support autistic people presenting with coronavirus symptoms.

To: Jackie O'Sullivan
<Jackie.OSullivan@mencap.org.uk<mailto:Jackie.OSullivan@mencap.org.uk>>;
[REDACTED] NR [REDACTED] @dhsc.gov.uk<mailto:[REDACTED] NR [REDACTED]@dhsc.gov.uk>>;
'Reeve, Simon' <simon.reeve@dhsc.gov.uk<mailto:simon.reeve@dhsc.gov.uk>>;
'Cienciala, Richard'
<richard.cienciala@dhsc.gov.uk<mailto:richard.cienciala@dhsc.gov.uk>>; Christine
Carson <Christine.Carson@nice.org.uk<mailto:Christine.Carson@nice.org.uk>>;
Rebecca Smith
<Rebecca.Smith@nice.org.uk<mailto:Rebecca.Smith@nice.org.uk>>; Helen
Jamison <Helen.Jamison@nice.org.uk<mailto:Helen.Jamison@nice.org.uk>>
Subject: RE: Do you have a contact at NICE?

Jackie,

To add a bit more to the reply below. Our COVID-19 rapid guideline: critical care was developed at speed to support critical care teams in their management of patients during this period of intense pressure.

We are aware that some people are concerned about the application of this guideline in relation to people with disabilities and learning disabilities.

The guideline says: "Base decisions on admission of individual adults to critical care on the likelihood of their recovery, taking into account the likelihood that a person will recover from their critical care admission to an outcome that is acceptable to them." Decisions about care for patients with disabilities or learning difficulties should be made with them and their carers as much as possible and they should not be put at an automatic disadvantage.

NICE will gather feedback on this suite of guidelines and review accordingly where necessary.

Best wishes
Paul

From: Jackie O'Sullivan
<Jackie.OSullivan@mencap.org.uk<mailto:Jackie.OSullivan@mencap.org.uk>>
Sent: 23 March 2020 15:06
To: Paul Chrisp <Paul.Chrisp@nice.org.uk<mailto:Paul.Chrisp@nice.org.uk>>;
[REDACTED] NR [REDACTED] @dhsc.gov.uk<mailto:[REDACTED] NR [REDACTED]@dhsc.gov.uk>>;
'Reeve, Simon' <simon.reeve@dhsc.gov.uk<mailto:simon.reeve@dhsc.gov.uk>>;
'Cienciala, Richard'
<richard.cienciala@dhsc.gov.uk<mailto:richard.cienciala@dhsc.gov.uk>>; Christine
Carson <Christine.Carson@nice.org.uk<mailto:Christine.Carson@nice.org.uk>>;
Rebecca Smith
<Rebecca.Smith@nice.org.uk<mailto:Rebecca.Smith@nice.org.uk>>; Helen
Jamison <Helen.Jamison@nice.org.uk<mailto:Helen.Jamison@nice.org.uk>>
Cc: Dan Scorer
<Dan.Scorer@mencap.org.uk<mailto:Dan.Scorer@mencap.org.uk>>
Subject: RE: Do you have a contact at NICE?

Thanks Paul

Would it be possible to have some clarity on whether the Clinical Frailty Scale applies to disabled people of working age and children? The key concern is that people with a learning disability who need support with daily living would be scored down to a level 5, 6 or 7, meaning that adverse decisions about treatment might be made.

If we could have something on that to put out to our audiences that would be very reassuring

Thank you

Jackie

From: [redacted] NR [redacted]@dhsc.gov.uk
Sent: Mon 23/03/2020 16:08

To:
Jackie O'Sullivan <Jackie.OSullivan@mencap.org.uk>; Paul Chrisp <Paul.Chrisp@nice.org.uk>; Reeve, Simon <simon.reeve@dhsc.gov.uk>; Cienicala, Richard <richard.cienicala@dhsc.gov.uk>; Christine Carson <Christine.Carson@nice.org.uk>; Rebecca Smith <Rebecca.Smith@nice.org.uk>; Helen Jamison <Helen.Jamison@nice.org.uk> [redacted] NR [redacted]@dhsc.gov.uk

Cc: Dan Scorer <Dan.Scorer@mencap.org.uk> [redacted] NR [redacted]@dhsc.gov.uk

Adding [redacted] NR [redacted] to the cc list.

From: Paul Chrisp <Paul.Chrisp@nice.org.uk>
Sent: 23 March 2020 19:49
To: Jackie O'Sullivan <Jackie.OSullivan@mencap.org.uk>
Subject: RE: Do you have a contact at NICE?

Dear Jackie

An update for you on our position.

NICE is very aware of the concerns of some patient groups about access to critical care, and we understand how difficult this feels. Our new COVID-19 rapid guideline on critical care was developed to support critical care teams in their management of patients during this very difficult period of intense pressure. The guideline says that on admission to hospital, all adults should be assessed for frailty, and that other

From: Paul Chrisp <Paul.Chrisp@nice.org.uk>
Sent: 23 March 2020 21:19
To: Jackie O'Sullivan <Jackie.OSullivan@mencap.org.uk>
Cc: Dan Scorer <Dan.Scorer@mencap.org.uk>
Subject: Re: Do you have a contact at NICE?

Hi Jackie

Sorry if this isn't clear enough. We will update the guideline in the next day or two to say that the CFS should not be used in some people including those with learning disabilities.

Paul

From: Jackie O'Sullivan <Jackie.OSullivan@mencap.org.uk>
Sent: 24 March 2020 07:48
To: Paul Chrisp <Paul.Chrisp@nice.org.uk>
Cc: Dan Scorer <Dan.Scorer@mencap.org.uk>
Subject: RE: Do you have a contact at NICE?

Hi Paul

That would be great. Thank you for your tweets overnight - these have gone some way, but people are still contacting us confused. It would be hugely reassuring for people to see the scale with 'not applicable to people with a learning disability or autism' on here.

It doesn't take much for people with a learning disability to get very jumpy about things like this. As you probably know, people still regularly die because doctors have misunderstood their condition - that's why the Government is introducing mandatory training in hospitals. But this hasn't happened yet, and we still get cases through where people have had 'learning disability' written on their death certificate or 'Downs Syndrome' on their DNR notice. It's pretty shocking.

Thank you

Jackie

From: Paul Chrisp
Sent: 24 March 2020 08:46
To: 'Jackie O'Sullivan' <Jackie.OSullivan@mencap.org.uk>
Cc: Dan Scorer <Dan.Scorer@mencap.org.uk>
Subject: RE: Do you have a contact at NICE?

Hi Jackie

That's good to know, thanks. As you can appreciate, because of the speed we were asked to produce these guidelines, they weren't subject to some of our usual steps. We are firming up how we get an Equalities impact assessment into all future topics. We are also devising a schedule for sign off on new topics, updates to the first ones, plus of course the rest of the therapeutically critical guidance that NICE must continue to produce. So we are looking this afternoon at changes to this guideline that take into account these concerns.

Thanks and best wishes
Paul

-----Original Message-----

From: Paul Chrisp <Paul.Chrisp@nice.org.uk>

Sent: 25 March 2020 13:52

To: Jackie O'Sullivan <Jackie.OSullivan@mencap.org.uk>

Cc: Dan Scorer <Dan.Scorer@mencap.org.uk>

Subject: changes to critical care covid guideline

Hi Jackie

Thank you for drawing our attention to the possible consequence of applying the CFS to people with learning disabilities. That consequence was not intended. It has been agreed to amend the guideline to read:

1.1 On admission to hospital, assess all adults for frailty, irrespective of COVID 19 status.

- * Use the Clinical Frailty Scale (CFS) for frailty assessment, available from the NHS Specialised Clinical Frailty Network as part of a holistic assessment of frailty.
- * Be aware of the limitations of using the CFS tool as the sole assessment of frailty. The CFS should not be used in younger people, people with stable long term disabilities, learning disabilities, autism or cerebral palsy. An individualised assessment is recommended in all cases where the CFS is not appropriate.
- * Consider comorbidities and underlying health conditions in all cases.
- * Record the frailty assessment in the patient's medical record

This amendment will be made as soon as possible. I hope that resolves the issue. We are intending to communicate this change more widely today.

Best wishes
Paul

From: Jackie O'Sullivan

Sent: 25 March 2020 19:28

To: Paul Chrisp <Paul.Chrisp@nice.org.uk>

Cc: Dan Scorer <Dan.Scorer@mencap.org.uk>

Subject: RE: changes to critical care covid guideline