DNAR: Background and Case Studies

Not surprisingly, given the threat from the virus, more attention is being paid to DNARs.

We are clear that DNAR Notices are, in themselves, not wrong. We do not want people to be afraid of having discussions about advance care planning and DNAR, or of making the choice that is right for them.

However, despite clear guidance that placing Do Not Attempt Resuscitation Notices (DNARs) on an individual's notes without consent is wrong, Learning Disability England's survey of our member organisations indicates that since the start of the Coronavirus crisis there has been some increased use of DNAR notices in the notes of people with learning disabilities without consultation with the person concerned, or the people who care about them.

The picture is nuanced, and it should be noted that our survey found that approximately two thirds of respondents did not report an increase in DNARs.

However, there are clear indications of the continued illegal use of DNARs since the start of the Coronavirus crisis in March in a number of cases and scenarios. In addition, there are circumstances reported to us where medical staff have made a clinical decision whilst an individual was critically ill without reference to the individual, their advocate, family or wider circle of support.

Despite the letter from senior NHS leaders to all NHS organisations reiterating clearly that blanket use of DNARs are unacceptable and the statements from the Royal Colleges, regulator and sector bodies reiterating this, 13 member organisations reported that they had seen an increase in blanket DNARs in March and April.

8 organisations had seen DNARs placed in people's records without consultation in March, and despite the publicity and clear guidance, 10 reported this happening in April.

As a direct result of the survey findings, Learning Disability England is now working with some members on additional resources that can support people to challenge poor processes or unlawful use of DNARs.

The following case studies give more detailed examples of what our members have experienced during March and April 2020 since the Coronavirus outbreak.

The following case studies have kindly been provided by Learning Disability England members. All identifying names and geographical locations have been removed to protect each individual's anonymity.

Case Study 1a: Lack of Informed Choice / Consent

The GP arranged a phone call with A to discuss a DNAR.

A was not given notice that this was what the appointment was about, and his staff team weren't told.

A communicates with very few words and his staff team felt that he wasn't able to make a decision for himself about a DNAR in the format given. He needed time and resources to support him to understand the decision. This was explained to the GP.

At that point, the GP decided that A did not have capacity to make the decision. The GP called A's sister almost immediately after the phone call with A, to discuss the issue with her. Neither A nor his staff team were aware that the GP planned to do this.

The manager then received a copy of a DNAR form for A, which stated the following as A's clinical problems and the reasons why CPR would be inappropriate, unsuccessful or not in A's best interests:

- *Known learning disability with developmental dyspraxia*

- *Known medical problems: asthma*

The form incorrectly stated that A's sister was his welfare attorney and the responsible person for making a decision.

The manager insists that A's support plan and attendant information had no reference to dyspraxia or asthma, and they were not aware of A having these conditions. The manager acknowledged this could possibly be because A receives less than 30 hours of support per week from the provider and does not need support in these areas, therefore his support team do not have a full picture of his health needs as recorded on the GP's file.

The manager has since discovered that the GP's phone call with A's sister was very brief and that the GP only gave worst case examples of where DNAR may not be successful. The manager and A's family felt strongly that the GP had failed to adequately advise on the medical implications of DNAR and the range of situations where it would be relevant to provision of treatment in A's particular case.

Following discussion between A, his team, A's sister and the manager, the manager has now written to the local authority, raising concern about the DNAR application and stipulating that A and his sister want paramedics and medical professionals to attempt resuscitation and rescue A's life in case of any incident.

A's Health Action Plan and Hospital Grab Sheet have also been updated to this effect, making it clear A and his family dispute any DNAR placed on his records by his GP.

Case Study 1b: Lack of Informed Choice / Consent

B was taken into Guy's Hospital by ambulance as she was displaying Covid-19 symptoms. When the results came back, 2 days later, the hospital wanted to send her home without any medical treatment. The Medical Registrar contacted the manager of B's service at 1.00am and stated that a DNRO would be put in place for B.

The manager questioned why the decision was made, to which the Registrar said B would not be able to accept or appreciate the treatment involved e.g. ventilator or understand why it was being done. Instead the hospital would be adopting 'End of Life and palliative care'.

The manager informed the Registrar that they were not in the position to agree to the decision as B has a circle of support who needed to be involved. The Registrar then said that she was not asking for an agreement and that it was a medical decision.

The manager asked the Registrar to contact B's family as they also needed to know. The manager then liaised with B's family who were also in agreement that the DNRO needed to be challenged.

The manager for B's support then contacted the hospital LD Nurse to ensure that this DNRO was not being enforced, as neither the family nor B's support providers agreed with it. The Registrar continuously stated that as B was not accepting the treatment then there was nothing that the hospital could do to support her and as such, they had put the DNRO in place and that it was a medical decision.

However, the home manager and the family continued to strenuously disagree with this course of action and stated that they needed to agree on a meeting to determine a Best interest decision regards this.

However, before this meeting was arranged or took place it was decided by the hospital and the home (with family involvement) that, as B was actually showing signs of recovery, that they would plan a discharge instead. The DNRO was not discussed by the hospital further. However, the fact that B was automatically put on a DNRO without consultation with her family or the home was very distressing for everyone involved.

Case Study 1c: Lack of Informed Choice / Consent

We received a phone call from the Registrar, a lovely doctor who explained that C had deteriorated overnight. He added at the end of the conversation that a DNAR had been put in place for clinical reasons. He explained that she would not have managed a ventilator due to underlying health conditions.

Despite there being a seemingly valid clinical reason for this outcome being reached, it didn't feel right at all. Even in this unusual crisis situation we are it didn't feel right to me that that a decision had been made without input from her social worker and advocate.

I contacted them immediately. C's advocate was unhappy that a decision had been made without consultation and he sought to challenge the decision. Fortunately, C's condition improved rapidly and she was discharged.

Case Study 2: Blanket Approach

The GP made contact with D's service to arrange 'welfare checks' for all the people registered with them. These checks were meant to include discussion about DNAR orders.

The manager of the service was resistant and felt the GP's surgery was not following due process around decision making.

D had a DNAR placed in her medical notes following the GP speaking with D's sister. The sister later told the manager that the discussion with the GP had not specifically covered the issue of DNAR and that she was shocked that a form had been added to her notes.

The manager was also concerned that the social worker for D had been engaged by the GP and was initially encouraging these 'welfare checks' to take place. Following further discussion with the manager, the social worker agreed that it did not sound as though the GP was following current guidance and due process in assessing and applying DNARs to people in the service.

Correspondence with the GP has made clear that the GP's practice considered they were acting on the basis of guidance from the local Clinical Commissioning Group (CCG) that they believed mandated advance care planning decisions using this approach. The provider has sent a Freedom of Information (FOI) request to the CCG to try and establish the issue in more detail. However, no further information about the guidance issued by the CCG has been provided to date.

Case Study 3a: DNAR came to light without individual or their representatives being aware

E was recently discharged from hospital with a DNAR in her medical notes. The reasons given for applying the DNAR on the record were:

- *Dementia*

- *Totally immobile – is hoisted*

- *Fully dependent*

E does not have any next of kin and the form does not list anyone as having been consulted or informed about the decision. There is no evidence provided of any form of individualised Best Interest process as is required in law.

The form indicates that the DNAR should remain in place until the end of E's life. No-one is listed for consultation in the section for reviewing the decision made by the hospital doctor.

E was discharged from hospital back to her support service. No one who supports her, including the manager of her support service, were informed that the DNAR had been added to her medical notes.

Case Study 3b: DNAR came to light without individual or their representatives being aware

F was discharged from hospital with a DNAR. The only reason given for why CPR would not be successful was that F has a learning disability.

F has a sibling, but it is not known whether they were consulted as part of the decision-making process.

Neither the support manager nor social worker were notified that the DNAR had been put in place. The manager has lodged a complaint with the hospital.

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