

Jenny Gibson

From: Manson, Helen <Helen.Manson@[GRO-C]>
Sent: 30 May 2022 16:35
To: caroline.leonard@[GRO-C]; Lee, Davinia; [GRO-D]
Cc: McKelvey, Debbie
Subject: CMcL

Apologies for the long email but I felt it important to be able to see the issues raised by CMcL to see if there is any process of resolve.

I have just had a phone call from CMcL regarding the letter that Mr Edward Conway received from Dr [GRO-D] dated 26/05/2022.

Not sure how this gets resolved, but CMcL is requesting a reply from yourself, Caroline, or Dr [GRO-D]

Jackie Dodds Patterson was present in the office during the call on speaker phone and helped record a phone call notes outline, so as to best represent CMcL concerns.

I have printed a copy of this email for the patient notes

Summary

- CMcL is not happy that we contacted Mr Conway by letter – she has expressed that we do not phone him **or send any letters to him**, as this has upset him and the family greatly. I did explain that as our patient, unless he has been assessed as lacking mental capacity, we would have to involve him in all aspects of his care. CMcL expressed that he **does not** have capacity ('Very vulnerable state and mind') and she acts on his behalf. I have said that we would need to ensure this is the case in order to best care for Mr Conway. CMcL expressed that I and we (the haemophilia team) were 'breaking the law contacting him.'
- CMcL discussed that she was not happy that the haemophilia centre were 'up to no good' – I did try to explain the simple reason from the blood sample not being tested for Liver Function – CMcL expressed that she was not interested in the answer I could give, despite me having the first hand information, and that this was Dr Benson's fault. Dr [GRO-D] was not involved in any way in the blood sampling that day, or in the review, nor was he even in Altnagelvin that day for the Altnagelvin clinic.
- Christina expressed that she was not happy with Dr [GRO-D]'s letter and the explanation of why the Haemophilia Centre can only do some blood tests that monitor liver function and that Hepatology have to do the rest – she expressed that this means all patients of the NI Centre are not having proper assessment of their hepatitis as only some tests are being done by the haemophilia team – she has said she will be passing on Mr Conway's letter to all the people she knows in Altnagelvin who have hepatitis to say they are not being properly looked after. I did try to explain that specialist care outlined in Dr [GRO-D]'s letter was regarding scanning and specialist Hepatology assessment. The Haematology team monitor liver function which is a predictor to further issues, which has always been the case, and that further issues are referred on to the Hepatology team. She expressed that she interpreted it differently.
- CMcL was also upset regarding a letter from the DVLA concerning questions around Mr Conway's liver function and alcohol intake – I did explain that I did not think that The Haemophilia Centre had any input in this as the DVLA information has to be processed by the GP – CMcL expressed that she did not believe me and it didn't matter anyway as Mr Conway no longer was driving.
Perhaps we could check if we had any input into this. From what I gather of previous correspondence, this was dealt with by Kevin O'Grady (social work team) and was referred back to the GP.
- Regarding Scanning – CMcL has expressed that Mr Conway was discharged from RVH Hepatology 'against his will', that they 'wanted rid of him' and Mr Conway did not attend the scans in Altnagelvin as 'Dr Ferguson is not a liver specialist.' I explained that myself and Dr [GRO-D] had reviewed Mr Conway's ECR notes and the Hepatology team had documented the following on an appointment on Clinic Date: 31/05/2019:

Dr McDougall writes,

'I explained to Mr Conway that we need to carry out an urgent MRI to characterise this small area in his liver. He said that he would much prefer to have the scan carried out in Altnagelvin because he finds the visits to Belfast very tiring. Therefore after the consultation was finished I contacted Dr Ferguson in Altnagelvin and asked him to arrange an urgent MRI scan of liver as soon as possible, hopefully within the next two weeks. I have advised Mr Conway that I will contact him as soon as I have the result of his MRI of liver and let him know if any further action is required.'

The liver scan has of date, not been performed.

CMcL has expressed that Mr Conway will not be attending Altnagelvin for the liver scan as Dr Ferguson is not a Hepatology Doctor. I did try to explain that as a gastroenterologist he covers general medicine, of which Hepatology is a part. She thanked me for trying my best but that should not try 'to make excuses for the team.' I explained that Haemophilia are a team involving many services including medical, nursing, social work, physio, OT and Psychology and that we all work together as a team for the care of every patient. CMcL expressed that Mr Conway did not have access to these services – I reassured, that the MDT reviewed Mr Conway at the last Altnagelvin clinic on 11.03.2022 and that some members were following up at his request. Claire Forde (OT) was contacting him with a follow up on some help with healthy sleep. CMcL has asked that this should not been done.

Unfortunately I was not able to pass this on to Claire Forde as she was contacting Mr Conway as CMcL was on the phone with me. Claire Forde did not have any issues raised during the phone follow up call she arranged with the patient at the last clinic. She also expressed to Mr Conway that that she would send him some information regarding healthy sleeping in the post, he did not offer any objections to this. I have asked Claire Forde to hold off sending these until we discuss.

- I did try to clarify that it was important that Mr Conway have blood testing for liver function as were trying to rearrange. CMcL again said she 'had it in hand and it was nothing to do with us'. She did say that the blood test had been completed and 'the results are very interesting.' There are no results logged or reported on ECR for the team to review.
- CMcL has expressed that Mr Conway has cancer in his liver and she wishes to remove Mr Edward Conway from the care of the Belfast Haemophilia Centre.

Many thanks for you all taking the time on this very challenging and time consuming case.
Helen

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Working together



Excellence

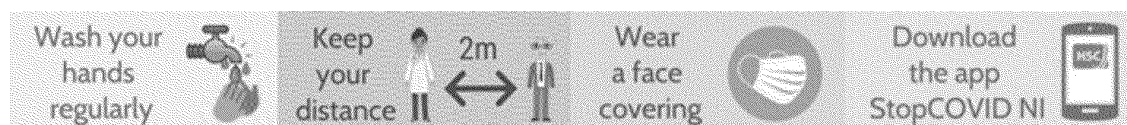


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