FOWLER'S
SYNDROME UK

Helpline Remit Policy

This document sets out the remit of the helpline service, FSUK.

FSUK advisers provide short term support, signposting and information for those who have Fowler's, their friends, family or medical professionals

FSUK provides this service over the telephone, via email and via text messaging.

The main elements of the service are for the user to be listened to, for diagnosis and treatment to be explored, and information and signposting given where appropriate. FSUK does not provide clinical advice, and does not have access to callers medical records.

In practice, an adviser will talk through the issues with the client, listening to their story, offering emotional support, and providing signposting regarding where or whom to receive help from dependant on the issues raised.

An adviser will also provide practical information regarding how to manage the practical aspects of Fowler's syndrome

For where the client is experiencing suicidal thoughts, the FSUK advisers are to follow the suicide and self harm pathway. Should the client tell us they are unable to stay safe from suicide and they are unable to reach out for help themselves, the FSUK adviser may need to pass brief details on to someone such as the emergency services in order to help them to stay safe. See FSUK's confidentiality policy for more information about this.

FSUK advisers are not counsellors

FSUK advisers cannot make referrals to other organisations, apart from those mentioned in the intervention policy to help someone to stay safe.

FSUK advisers cannot make calls on behalf of others, and they cannot contact someone unless that person has reached out to the service themselves first.

FSUK does not provide a face to face service. In the event that a potential client tries to access help by visiting any of the FSUK offices, they will be re directed to contact the helpline by phone, text or email. FSUK advisers or other staff members are not trained in offering face to face help.

FSUK does not undertake casework on behalf of clients. It is not within FSUK's remit to undertake any other work on behalf of clients after the contact has ended other than

sending through an SMS or email with details of organisations that have been suggested, if the client would like this information. Signposting and advice

FSUK can provide a signposting service. Signposting means giving a client details of an organisation (phone number/opening hours, for example) and explaining what that service does, if this is deemed appropriate throughout the conversation.

If someone calls FSUK and doesn't get through right away, we would strongly encourage them to leave a voicemail stating their contact number, and an adviser will return their call as soon as one is available. If someone were to continually call, this one-way call traffic could cause a problem for advisers working on call-backs. For this reason, always call once and leave a voicemail.

Due to the nature of FSUK, the majority of contacts will be one-off support, or people may contact FSUK again to follow up on advice, to review a plan, or for emotional support.

Regular callers are those that may call back multiple times. In order to ensure that they receive appropriate support, the FSUK advisers may keep some notes, in line with the Data Protection Act (1998), on what has been discussed and advised, and they will also review that client's use of the FSUK service regularly.

If it is deemed that FSUK has become a barrier for a client accessing further support, or if there is no more practical advice and support that FSUK can provide for that individual, the service may be withdrawn for that client, often for a set period of time.

If FSUK withdraws the use of its service to someone and they get in touch via text or email during the withdrawn period, FSUK will not be able to see these messages.

If the client calls, their number will either be unable to get through to FSUK, or the adviser will end the call after explaining why if the call did connect.

Test calls: These are contacts from a single client or group of people that are intentionally misusing the service, such as by making 'prank calls' to the service. In most circumstances it will be necessary to end these calls, and details can be passed on to the police if someone were to continue to misuse the service in this way, as this can prevent people who need help from being able to get through to the service.

Some test calls may be a result of someone finding it really difficult to start a conversation and it may sound as though nobody is speaking. In these cases, the FSUK advisers may start by explaining some things about the service to give the caller some time and space to feel more able to talk. They may also encourage the caller to call back when they feel ready to talk, or to contact the service via text or email in case they find this more helpful.

Sexually inappropriate calls: If a caller is sexually inappropriate on the call, text, or email service, the FSUK adviser will offer one warning, if that warning is not heeded they will end the contact.

Abusive or aggressive calls: If a caller is abusive or aggressive towards the adviser on the call, text, or email service, the FSUK adviser will give one warning, and then end the contact.

Clients with learning difficulties or speech impairments: In these cases, it will be helpful to let the FSUK advisers know whether there is anything they can do to help with any difficulties in communication or understanding. The FSUK adviser will seek to support the client using whatever means they choose to contact an adviser, but they may suggest alternatives if they seem more appropriate.

If the caller is under the influence of alcohol or other substances: FSUK advisers will always try to support someone who contacts for support. If the person is under the influence of alcohol or other drugs but can work with the adviser, then the contact will continue as usual. If it seems as though the person cannot engage with this contact and cannot work on safety, then the adviser may end this contact and encourage the client to reach out for emergency support. The intervention policy may also come into effect during these times, see confidentiality policy for more information.

Policy Review and Amendments: This policy will be reviewed annually, by the end of the first quarter (Q1), to ensure that it continues to meet the needs of FSUK and its community.

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Reviewed and agreed by [IH, HE]