

Royal College of Physicians of Edinburgh

Call for views

National Care Framework for Huntington's Disease- draft

The Royal College of Physicians of Edinburgh (“the College”) was founded in 1681. We support and educate doctors in the hospital sector throughout the UK and the world with over 12,000 Fellows and Members in 91 countries, covering 30 medical specialties. We welcome the opportunity to submit comments on the draft National Care Framework for Huntington’s disease.

The College welcomes the interactive version of the framework and commends this excellent approach which is person centred.

A lot of the content is more general in nature, with some specific issues rightly highlighted more explicitly, which is appropriate given their significance for both the family and the health professional.

It may be helpful to include a general outline of the areas of function most likely to be affected and the range of variation that should be anticipated by health carers, especially in terms of cognitive function and deterioration and risks for mental capacity being lost, when legal autonomy may alter.

There seems to be an assumption that every patient will have family around them and being affected by their condition, but there may need to be more acknowledgement of the needs of isolated individuals as the College understands this is also an issue.

Clarification would be welcome in terms of how the framework would fit in with existing standards and current service provision, resourcing and outcomes.

Overall the College welcomes this approach and suggests it may be a good template for other conditions.

Further copies of this response are available from Lesley Lockhart (tel: 0131 225 7324 ext 608 or email: l.lockhart@rcpe.ac.uk)

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