

Dear

I thought I would pass on the thoughts from carers & some patients in DeNDRoN discussion groups about DOMINO recruitment issues.

BELOW IS A SUMMARY OF KEY POINTS RAISED (For background, reports are attached):

Stopping donepezil to join the DOMINO study

- Stopping donepezil to join the study, at a particularly difficult stage of the illness, was a potential concern. If a patient on donepezil were in “a manageable situation”, carers said that they would be wary of risking inviting “unnecessary disruptions”.
- Even with an option to go back onto the pre-study dose of donepezil if a patient began to decline on the study drug, carers said they had concerns about a potentially drawn-out recovery period.
- As some clinicians follow these NICE guidelines more firmly than others, one query was whether DeNDRoN’s focal point for recruiting more patients might be to concentrate on the clinicians who are firmly following the NICE guidelines.

Explaining the study

- More time explaining the study could help. It was felt that doctors and nurses should be especially encouraging about DOMINO providing a 3 in 4 chance of remaining on an active medication.
- Specialist Nurses were felt to be key to explaining the study.

Carer fatigue

- Fatigue and time pressures among carers may be recruitment and retention issues. It was suggested to add new elements to the DOMINO research visits aimed specifically at ensuring they are a positive social experience for carers.

Other suggestions from carers

- Make GP referrals to the study easier.
- Keep up efforts to go directly to patient groups to increase local awareness.