

# Nursing home carers' perspectives on caring for residents with dementia presenting with muscle tone changes

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## Background & Aim of the Study

Paratonia is a form of increased muscle tone observed in people with dementia (PwD). Signs of paratonia have been observed in people with mild and moderate dementia<sup>1</sup>, but it is thought to be present in most people with advanced dementia<sup>2</sup> and affect personal care<sup>3</sup>. While understanding of the aetiology, prevalence and management is increasing, little is known about the impact of paratonia on caring for PwD. This study aimed to explore understanding of paid nursing home care staff of paratonia and experiences of its impact on care for PwD.

## Method

Two nursing homes in Bristol with residents with dementia were purposively selected and paid care staff recruited through advertising. Focus groups were conducted at each nursing home; a total of 9 care staff participated. Information about employment and training was collected. Focus groups were audio-recorded, transcribed verbatim and thematic analysis conducted utilising Braun and Clarke (2006) 7 stage process. The term 'muscle tone changes' was used with carers as paratonia is not a widely recognised term.



### Participants

Nursing Home 1	Nursing Home 2
All female (5)	All female (4)
All NVQ level 2 or above	No formal qualifications
Length of time as a carer: 6 years – 34 years	Length of time as a carer: 6 months to 28 years
All received dementia specific training	2 had received specific dementia training
All residents assessed by in-house physiotherapist on arrival and guidance given on handling during personal care.	Ad-hoc training on handling if residents referred to an NHS physiotherapist

## Findings

See an inevitable static end point

- "It's **just going to get worse** and then we'll never get in there" (NH2)
- "it's all starting to happen and **eventually it's all going to go like that**" (NH1)
- "So I think she's at that stage now when she's **going to start with that stiffening up**" (NH1)

Using 'soft skills' to provide person-centred care

- "talk to them and calm them down, in a **soft voice**, not in an aggressive voice, or anything, a nice soft calm voice and that tends to work" (NH2)
- "take your time" (NH1 and 2)
- "you try and **be really gentle**" (NH1 and 2)
- "you know **each resident's different** and understanding what makes them laugh.." (NH2)

Want to be able to help

- "we try and ask him to stand up, or you know, walk straighter" (NH1)
- "if we was to know the signs at the beginning of it then we can think, well hang on, **the signs are there, we need to go and speak to someone higher up**" (NH2)
- "we don't know the **actual proper way of doing it**" (NH2)

Perceive risks and consequences of providing care

- "you are **frightened you are going to hurt them...** because some of them are so delicate, like you feel like you're breaking their arm or something, it's, imagine that and how you would feel after do you know, **you'd feel terrible, I think I'd have to leave and never come back**" (NH2)
- "you have more of like a **fight to get their clothes on....** It is not just hurting them, really we are straining ourselves as well" (NH2)

- Care staff were able to see dynamic and static stages of the dementia process but did not attribute these specifically to muscle changes.
- The focus was on caring for the individual, achieving the end goal of maintaining hygiene and using strategies to 'soften' the impact of their intervention.
- Care staff identified the benefits of training on increasing awareness and felt that they were in the best position to identify when it is starting to become harder to manage the care needs of the resident.

## Conclusions

This small scale study of care staff in two nursing homes in Bristol gives some insight into their thoughts, concerns and strategies for managing this cohort of residents. Knowledge of paratonia or which issues are specifically attributed to the muscle tone changes was limited, but their focus was on providing care, rather than the health status of the resident. They recognise that they may be best placed to identify those residents at risk with appropriate training.

## References

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