

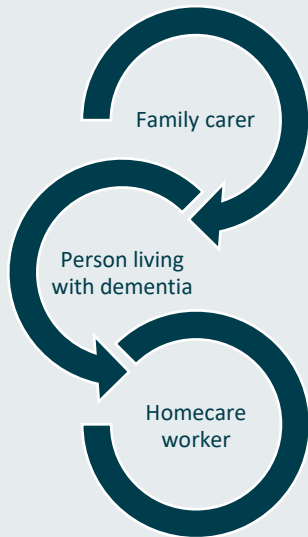


UNIVERSITY of
BRADFORD



UCL

NIDUS



NIDUS-family

NIDUS-family professional

NIDUS-Professional Road Map

1. We built an evidence base...



2. ...used it to co-produce NIDUS-Professional (Sept 2019 – April 2020)



3. ... piloted it in one group of home carers (November 2020 - March 2021)

COVID-19 update: NIDUS-professional was adapted to remote delivery via Zoom video call.



4. ...and test it in randomized feasibility trial (60-90 home carers from 3 agencies and 60-90 clients with dementia) (Sept 2021 – July 2022)



5. Analysis

professional



Planning and enabling meaningful patient and public involvement in dementia research

Alexandra Burton^a, Margaret Ogden^b, and Claudia Cooper^a



New experience for me - wasn't quite sure at times re how to position myself amongst the other coproduction participants - perhaps could have met individually with researchers initially? (professional)

'You can say anything – it's just a case of saying it. No one judges you. You can say what you feel' [PLWD]

'You know, they are a nice team to work with, everybody was. So we weren't just there as token...we did bring our views and I think they were taken on-board ...I think that was one of those where we worked quite well' [Family carer]



Pilot study findings

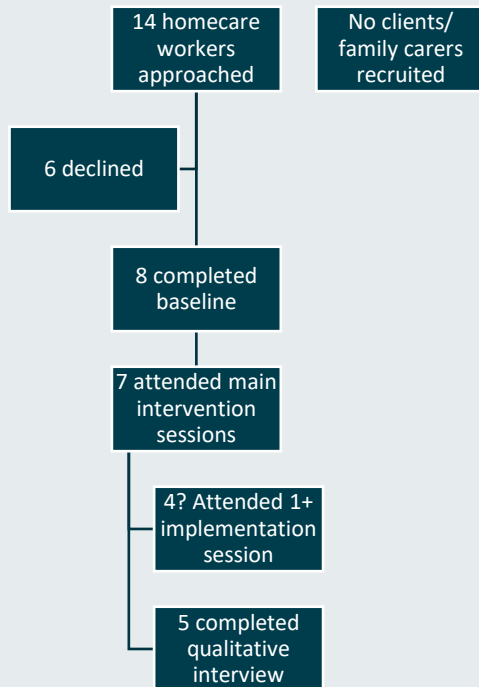


Table 1. Baseline characteristics of participants.

<i>Results are n (%) unless specified otherwise</i>	Completed baseline (n=8)	Completed intervention (n=5)
Age (years), mean (SD)	39.6 ()	43.2 ()
Gender		
Male	1 (12.5)	1 (20)
Female	7 (87.5)	4 (80)
First Language		
English	7 (87.5)	4 (80)
Punjabi	1 (12.5)	1 (20)
Ethnicity		
White British	7 (87.5)	4 (80)
Asian or Asian British: Pakistani	1 (12.5)	1 (20)
Highest level of education		
O levels/GCSEs	3 (37.5)	2 (40)
Vocational (NVQ, GNVQ, BTEC)	3 (37.5)	1 (20)
Degree	2 (25)	2 (40)
Received any training in dementia?		
No	2 (25)	1 (20)
Yes	6 (75)	4 (80)
Job title		
Home care worker	6 (75)	4 (80)
Home care worker (supervisor)	2 (25)	1 (20)
Working hours		
Full time	5 (62.5)	3 (60)
Part time	3 (37.5)	2 (40)
Duration working at the agency		
Less than 6 months	4 (50)	3 (60)
1-3 years	3 (37.5)	2 (40)
5-10 years	1 (12.5)	0
Duration working in home care overall		
Less than 6 months	4 (50)	3 (60)
1-3 years	3 (37.5)	2 (40)
10 years or more	1 (12.5)	0 (0)

Pilot study findings

Table 2: Attendance (Group, Group Catch Up, Individual Catch Up, Not Attended)

Participant (Gender, Duration working in home care)	Session Number						Post Intervention
	1	2	3	4	5	6	
P1 Female, Less than 6 months	G	G	G	G	GCU	G	Interview
P2 Female, 1-3 years	ICU	G	x	x	x	x	No
P3 Male, Less than 6 months	G	G	G	G	GCU	G	Interview
P4 Female, 1-3 years	G	G	ICU	G	GCU	G	Focus group
P5 Female, 10 years or more	ICU	G	x	x	x	x	Interview
P6 Female, 1-3 years	G	G	G	GCU	ICU	G	No
P7 Female, Less than 6 months	G	G	G	GCU	GCU	G	Focus group

* G = attended group, GCU = attended group catch up, ICU = attended individual catch up, x= did not attend.

** P8 withdrew before intervention delivery began as planned to leave the agency so no longer eligible (eligibility criteria: plan to remain working in the agency for 6 months or more)

Attendance at Group or catch up: 34/40 (85%) of possible attendances by eligible participants (34/48 (71%) of those originally consented)

How acceptable is intervention to deliver in practice? How did homecare workers perceive its value to them and their work?

Having space to reflect

Time to reflect

A safe space to reflect with peers

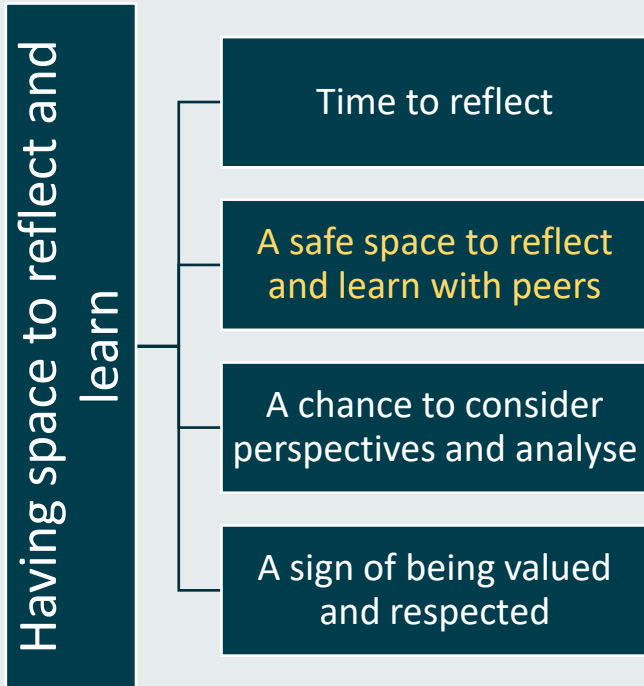
A chance to consider perspectives and analyse

A sign of being valued and respected

Homecare is time pressured; time to reflect and relax could help leave some of the stress at work

- *“...at the end of every session they did a self-relaxation technique, which I think is absolutely fantastic...it’s there to make you aware, like, make sure you take that time at the end of a shift to just relax yourself, because, like, even for me, as a new person, I feel like I do sit at home sometimes and I’m worrying about that client that I’ve been to, and I think, she’s got a chest infection, I hope she’s okay, and so, kind of like, having these relaxation techniques to take your mind off, and unwind at the end of a shift, because it is very full-on and very fast-paced. So, that was a really good...” (P7, focus group)*

How acceptable is intervention to deliver in practice? How did homecare workers perceive its value to them and their work?



Though some would have preferred f2f, interviewees enjoyed sessions, chance to meet peers especially valued

“Quite relaxed, I think everyone actually enjoyed the call...everyone wanted to input, sort of thing, because we all wanted to learn from it, and we’ve all got a story to tell” (P4, focus group)

“I wasn’t sure how it would be on zoom, if you’d asked me I would have been a bit doubtful but it worked really well. Going forward I would say use both, blended would work best” (P3, interview)

“It didn’t feel like a chore, you felt, I always looked forward to it, because it didn’t, you weren’t like, two hours sitting there listening to someone tell me about how to be a carer, it was like, I’m really excited to see what everyone’s been up to this week and see what examples, what we’re going to talk about this week.” (P7, focus group))

shifts cross, so a cleaning shift might cross with a lunch shift. But otherwise, you very rarely see them, and I think that’s why it’s so important to have these groups. So, you feel like you’re part of a team, you don’t feel so alone.

if a client is really refusing any treatment, or they're really confused, you might feel like, they don't like me, but ... we talked about looking at the surrounding environment, see if anything's changed that's made them this way, rather than just assuming, well, it's me, or they don't need anything so I'm going to leave, it makes you evaluate the situation a little bit better.

Reflecting increased understanding of what was happening during care; sharing real life examples valuable but sometimes hard

"There's been more reflecting for me, thinking about what happened for a few minutes after visits since the training, before when the visit was over that was it, on to the next one. Before the training the only reflection was reading notes from the last person, since the training there's been more conversations with other carers (P3)

[Client] has more trouble with getting up in the morning. I mentioned the training and we thought about how we could do things in a different order. [interviewer – do you think it changed how you delivered care?] I think Margaret would have noticed the difference, because she bruises quite easily and previous she had to give quite a bit of instruction about how to lift her and so forth. But she's had to do less of that now as we talk between each other"

Having space to reflect and learn

Time to reflect

A safe space to reflect and learn with peers

A chance to consider perspectives and analyse

A sign of being valued and respected

Real life examples helpful for learning but challenging

"And it's not even about a repetition, because obviously, when they ask us for an example, some people give the same example they gave last week, so we go through it again, does that make sense? (P4, focus group)

Being valued by organization/ facilitators helped to value own skills, own time, own feelings?

Time to reflect

A safe space to reflect and learn with peers

A chance to consider perspectives and analyse

A sign of being valued and respected

Being valued

Valuing self

"...they asked you questions, 'Do you feel valued?' and stuff like that. Yes, I thought it was really interesting, and I think that was really good, that bit." (P1, interview)

"There are 200-300 carers in my organisation so I feel lucky to have got to do it – people who I've told about it have said nobody offered me that" (P3, interview)

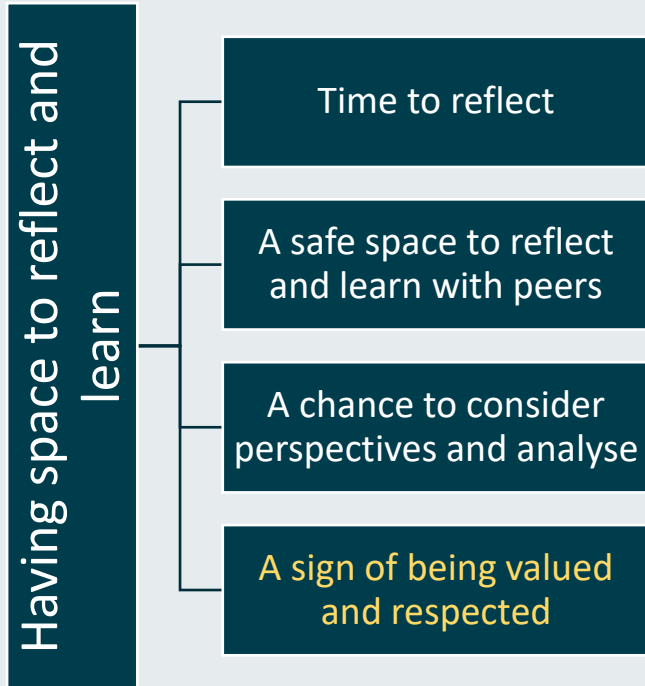
she remembered something that [F1] had said three weeks before, and she would link it back to that, and that was really good to think, gosh, they are actually listening to us as people, and they're not just there to give a job, they genuinely felt, seemed really interested in us as people" (P7, focus group)

I think a lot of the things that are described and a lot of the techniques that we're taught about actually, we do implement on a daily basis, but we didn't realise that we do it

(P4, focus group) "you build up a lot of relationships with a lot of clients, and especially this year, quite a few of them have passed away, and it's really quite sad. And you miss them, because you've got that relationship, it's like seeing your family every day. You visit them every day, look after them, and it's just having support and knowing how to deal with that, really"

that's one of the things I'm struggling with, saying okay, my 45 minutes is up, do you need anything, because I need to leave now.

How acceptable is intervention to deliver in practice? How did homecare workers perceive its value to them and their work?

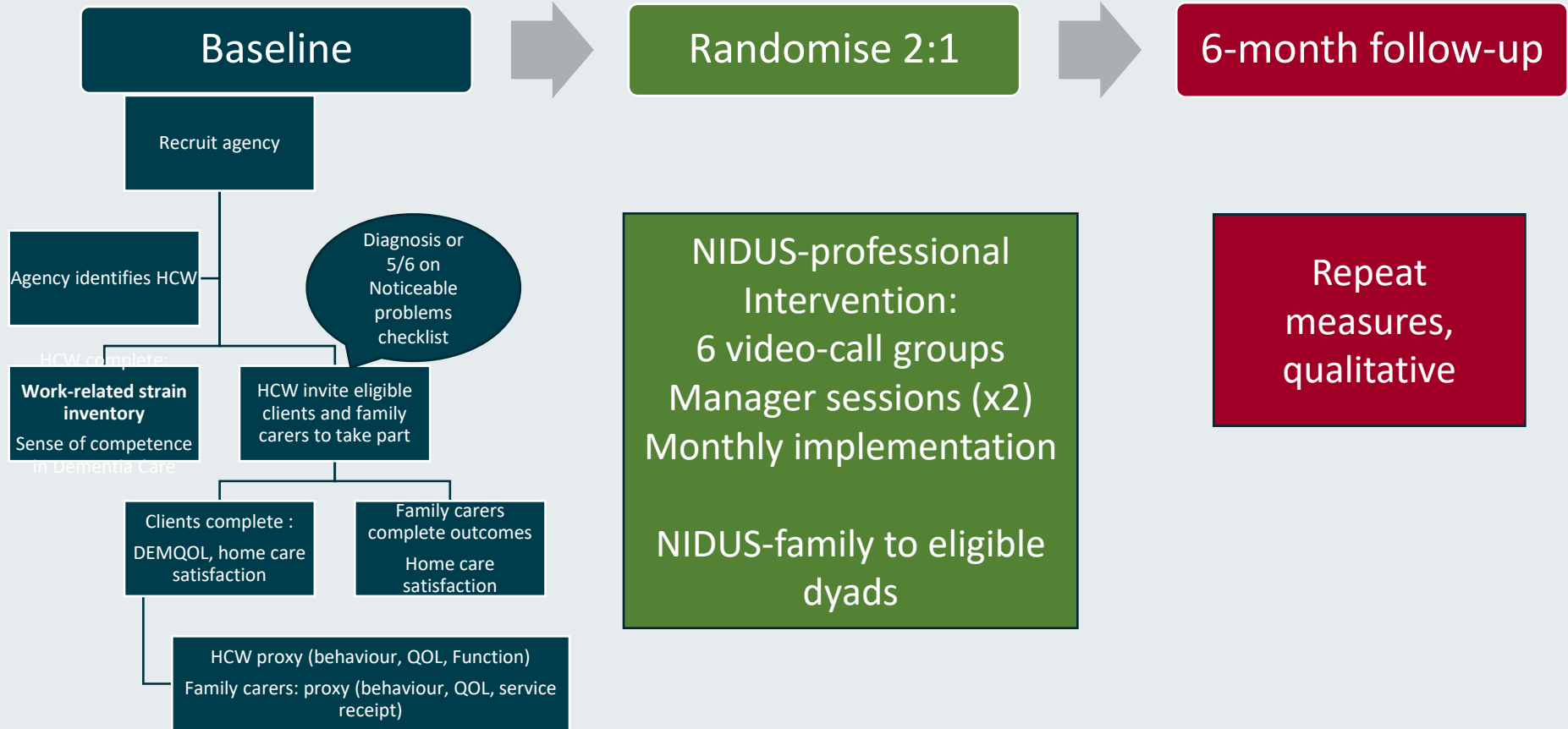


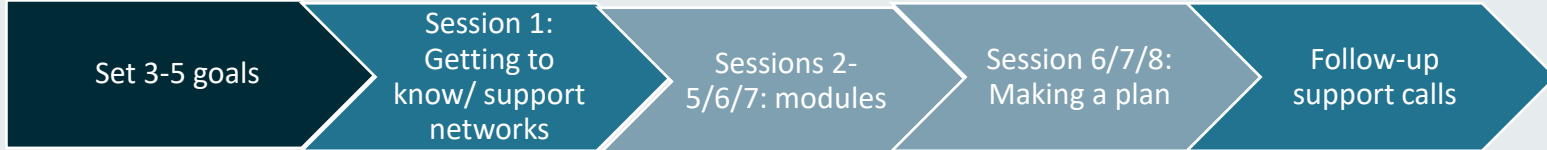
- Homecare is time pressured; time to reflect and relax could help leave some of the stress at work
- Though some would have preferred f2f, interviewees enjoyed sessions, chance to meet peers especially valued
- Reflecting increased understanding of what was happening during care; sharing real life examples valuable but sometimes hard
- Being valued by organization/ facilitators helped to value own skills, own time, own feelings?

NIDUS-professional randomized feasibility study

- Are criteria for progression to a full trial:
- adherence of home care staff to the NIDUS-professional intervention (4/6 group sessions)
- completion of follow-up measures by service clients and staff (75%+)

NIDUS-Professional Feasibility study

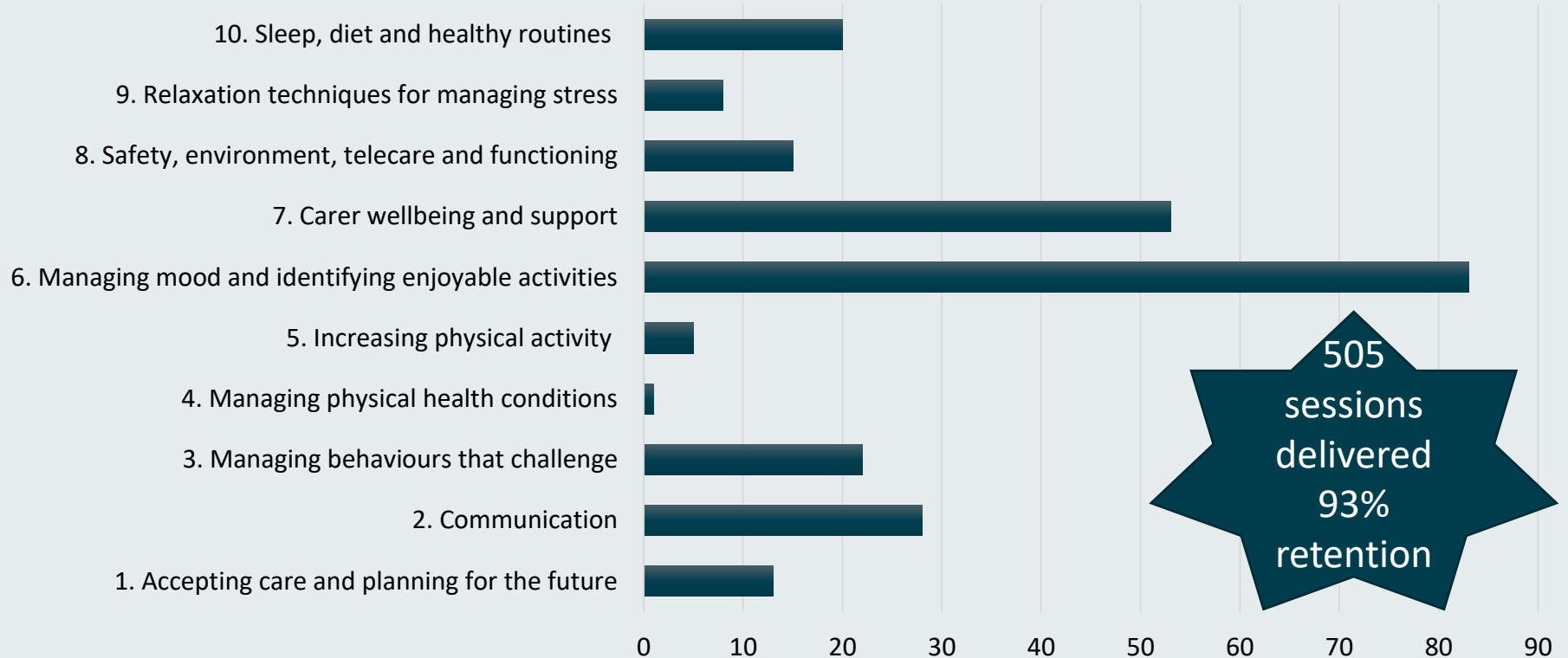




Goal Area:	Increasing Physical Activity	6 month Follow-up		12 month follow up	
		Carer Rating	Clinician rating	Carer Rating	Clinician rating
Much Better (+2)	PLWD goes out for a walk or other form of physical activity (at least 20 mins) 4 or more days a week				
Goal (+1)	PLWD goes out for a walk or other form of physical activity (at least 10mins) 3 days a week.				
Baseline (0)	PLWD used to love cycling 3 times a week and walking 4-5 days a week. He appears to have less motivation to be as active, his motivation started declining about a year ago and has got worse. He is now no longer cycling and is only walking 1-2 times a week				
Worse (-1)	PLWD is only going out for a walk once a fortnight or less				
Much Worse (-2)	PLWD is no longer going outside for any physical activity.				

Goal Area:	Break from caring	6 month Follow-up		12 month follow up	
		Carer Rating	Clinician rating	Carer Rating	Clinician rating
Much Better (+2)	The carer has a break from her caring responsibilities for 4-6 hours a week.				
Goal (+1)	The carer has a break from her caring responsibilities for 2-3 hours a week				
Baseline (0)	Once a week the carer has 1 hour where she can have a break from caring responsibilities and do something for herself (she goes for a walk with a friend). Other than this 1 hour, she has no other time for herself.				
Worse (-1)	Once a fortnight the carer has break from her caring responsibilities for 1 hour or less				
Much Worse (-2)	Once a month the carer has a break from her caring responsibilities for 1 hour or less				

Number of sessions delivered in each NIDUS-Family Module



Caring and negative emotions

Caring for a person with dementia can be stressful. Family members caring for people with dementia have told us that they sometimes feel:



Looking after yourself: making a BASE plan



Planning Record: BASE activity planner

	Being healthy	Activity	Social	Enjoyment
MON	_____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
TUES	_____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____

Comments on NIDUS-family:

"I have found NIDUS invaluable and am very grateful for what I have learnt."



"The sessions have allowed me to accept the current situation and understand why he (husband) can't do certain tasks. It has made it easier for me to adjust my expectations and reactions."

"The sessions have helped me to recognise I was being too hard on myself. I now actively make time to congratulate myself and look after my own wellbeing."

"The sessions have helped me become more aware of my own beliefs and judgements."

"It was lovely to have someone to talk to regularly over the lockdown, I will miss our chats. I felt able to talk so openly about my situation in a way I normally don't."

"the sessions are helpful because they give you a chance to step back and think about your situation and make changes that you would find difficult to do on your own."

Are you a home care agency with clients living with dementia?

Would you like to help us test a new training course for home care staff?

What happens if my agency takes part?

- ✓ All your staff who provide care to clients with dementia will be invited to complete questionnaires at the start of the study and 6 months later
- ✓ We will ask you to invite your clients with dementia, and their family carers if they have one, to complete questionnaires
- ✓ All questionnaire responses will be confidential

If your agency is allocated to receive NIDUS-Professional Intervention:

- ✓ The training will be in groups of 6-8 staff in six, 1 hour sessions (on zoom) over three months. It is fun and interactive and your staff get a certificate on completion.
- ✓ After the training, the facilitators keep in touch for three months to offer support.

We will reimburse organisations for their time (£20 per hour).

If you are interested in hearing more, please contact **Larisa Duffy**
Email: larisa.duffy@ucl.ac.uk

