



LINK Report: The Availability and Quality of Respite Care in North Tyneside



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1. Introduction

The issue of respite care was raised at the LINK launch events early in 2009. Particular concerns included

- People don't know what they can access
- Not much respite for young people
- Services are oversubscribed
- Lack of small breaks

Six main priorities were identified by the LINK Board for immediate action whilst a further four areas, from the top ten identified by members, were to be followed up at a later date. Respite care was one of these four areas. 55 members contributed to the priorities identified at the launch events with 15% of members identifying respite care as one of their top five priorities.

As a result, in September 2009, the LINK Board decided that it wanted to see an investigation into current respite provision, and how adequate service users and their carers feel it is. The Board decided to commission this piece of work and encouraged applications from members. It was advertised on the LINK website and in Stronger Voice. After an interview process, it was decided that Sheila Lambert of St John's Ambulance Northumbria would carry out this investigation.

The following is Sheila's report for LINK.

2. Background Information: Respite Care

The definition of North Tyneside Council's 'breaks service' (also referred to as respite care) is one which actually gives the carer a break from direct responsibility of supervising or caring for the relevant person by providing a service to that person.

A breaks service must always aim to provide a positive experience for the service user as well as a break for the carer.

It should be noted that although a breaks service is provided for the benefit of the carer, it is actually provided to the Service User, and where it includes personal care, it must be provided as a community care service under the NHS & Community Care Act 1990 and not as a Carer's service under the Carers and Disabled Children Act 2000. If a direct payment were given in lieu, it would therefore go to the Service User and not to the Carer.

A maximum of 8 weeks respite care can be accessed per year, in a residential or nursing setting, dependant on need.

There is quite a lot of confusion as to what constitutes 'respite care' and many carers are happy with the short breaks provided by the Service User attending a Day Centre.

However for the purposes of this report, respite care, except where stated otherwise, is deemed to be in residential accommodation.

3. People in North Tyneside Accessing Respite Care

Table 1: Number of clients receiving Respite Care by Client Group in the period 1 April 2008 to 31 March 2009 (source: North Tyneside Council)

Main Category	Age		Total
	18-64	65+	
Physical Disability & Sensory	17	155	172
Learning Disability	134	0	134
Mental Health	21	86	107
Other Vulnerable	4	2	6
Total	176	243	419

Table 2: Number of clients receiving Respite Care by Provider in the period 1 April 2008 to 31 March 2009 (source: North Tyneside Council)

Service Provider	Age		Total
	18-64	65+	
Annitsford House	1	1	2
Appleby Nursing Home		1	1
Ashfield Court		1	1
Ashley House		1	1
Bamburgh Crescent	19		19
Beechwood Residential Home		7	7
British Holidays	1		1
Byker Hall Nursing Home	1		1
Calvert Trust	2		2
Charlton Court		1	1
Cleveland Park Nursing Home		1	1
Collingwood Court		2	2
Comm MH Resource Centre	3		3
Dorset House	3	174	177
Eothen Homes		2	2
Fordley Short Break Service	45		45
Gailey Lodge	1		1
Harwood Court		1	1
Heatherfield	1		1
Hollybush House		1	1
Lismore		2	2
Manor Road Residential Home		1	1
Meadway House		1	1
Mental Health Matters	13		13
Monks Haven Hotel		3	3
Not Recorded	13	10	23
Preston Towers		1	1
Redesdale Court		1	1
Solway House		1	1
Springfield Park Rest Home		1	1
St Anne's Rest Home		11	11
Stanton Lodge Nursing Home	7	4	11
Starting Point	8		8
Swan Lodge Nursing Home		5	5
The Lenore	1		1
The Royal Air Force		1	1
Victoria Lodge Res Care Home		1	1
West Farm	53		53
Willow Lodge	1		1
Woodlands Respite Car Centre	2		2
Total	176	243	419

Those eligible for respite care had been assessed as having a critical or substantial need.

4. Type of Respite Care Available

Within North Tyneside there are a number of services offering respite care breaks, for a variety of needs.

Council run establishments include:

Addison Street Short Break Care Unit

This is a North Tyneside Council facility (at no charge to the individuals' families) for short break care for 8-18 year olds.

It has 5 beds and caters for approximately 40 Users who access the service every 4-6 weeks (total allocation is 42 nights per year) depending on their circumstances.

Breaks are usually from Monday to Friday, or over a weekend: holiday stays are available of up to 14 days. Breaks must be booked in advance and there is a waiting list (8 at the time of the visit).

Users are referred to this Unit by Care Managers on the Children's Disability Team and have a physical disability or suffer from challenging behavior e.g autism.

While at Addison Street, (unless on a holiday break), Users continue to attend their regular placement e.g school, college etc and activities are arranged for them in the evenings and weekends.

Fifteen staff are employed at Addison Street and work on a rota system. The staff working at the time of the visit felt that nearly all the users enjoyed their time at the centre and the respite provided was beneficial to their families.

It was mentioned that some Users/Families would benefit from a greater allocation of time at the Unit, and more space for a playroom and additional sensory equipment would be advantageous.

NB. Additional properties are being renovated by North Tyneside Council to provide two respite and four residential beds.

West Farm & Fordley Short Break Services

West Farm and Fordley are North Tyneside Council operated short break services for adults between the ages of 18-65 years who have a learning disability, some of whom may also have a physical disability. A minority of Users have challenging behaviour.

There are 6 beds at West Farm, all on ground floor level, which are fully used by 54 Service Users; there was no waiting list in operation at the time of the visit.

The 6 beds at Fordley are on two floors and accessed by 56 Service Users. Twenty users have physical disabilities (12 having complex health needs) and tend to use the downstairs bedrooms. At the time of the visit, a waiting list was in operation for downstairs rooms.

Users are referred to both Units by Care Managers (their need having been assessed as critical or substantial). Fees are subject to financial assessment and allocation is between 14 and 56 days.

Breaks are booked in advance and Users will often request stays with friends who also use the service. Breaks can vary from 1 night to month long.

Transport is not provided by the Unit and Service Users tend to use their Day Service transport, family transport or arrange taxis independently.

At West Farm 14 staff work on a rota system and when fully staffed, Fordley has 13 staff.

While at the Units (unless on a holiday placement), Users continue with their regular routine during the day and attend their placements at work, college, day services etc. Activities are arranged for Users in the evenings and at weekends.

Activities are arranged to suit the preferences of the Users and include for example meals out, visits to clubs, trips to the cinema and pantomime, church services etc. Participation in new activities is encouraged.

Users are enabled to develop daily living skills (e.g. shopping, cooking etc) and the break at the Unit is often a starting point for someone to move on to a supported living scheme.

The staff at both Units felt that all the Users enjoyed their time there: they looked forward to it and often viewed it as a holiday.

At West Farm it was felt that Service User stays could be more flexible if a nurse was based on site.

Dorset House Resource Centre

Dorset House is operated by North Tyneside Council for Service Users who are over 65 (will take younger in exceptional cases) and holds registration for Older People and Older People with a diagnosed dementia.

There are 41 beds at Dorset House, mainly used for respite breaks, but also for rehabilitation following hospital discharge.

Assessments for short break placements are made by Care managers and based on need: financial assessments determine charges for the service.

4.1 Additional Providers of Respite Breaks

Additional providers of respite care (and the number of beds provided) can be seen in Table 2 above.

Out of area respite breaks have been accessed at the Calvert Trust in Keilder, the RAF establishment in Rothbury, Woodlands Resource Centre in York and Leuchie in Berwick.

5. Accessing Respite Care

A number of service users (individually and in focus groups) and their carers were asked about their experiences of respite care (**Appendix 1**). All the service users questioned were over 65 years of age and therefore did not use Addison Street, Fordley or West Farm Units. The vast majority used Dorset House for their breaks.

5.1 Case Studies

A number of case studies have been used to depict personal experiences of accessing respite care (**Appendix 2**).

5.2 Evidence of waiting lists to show unmet need/demand

Although there was no evidence of waiting lists for respite care breaks for those over 65, some individuals who were eligible did not take it up. This was most noticeable from those caring for someone with dementia (source: Alzheimer's Society), who felt that the standard of respite care available was so poor that they did not feel they could access it for the person they cared for.

5.3 Evidence to suggest that different services are needed or that existing services should be delivered in a different way

There was clear evidence from the interviews and focus groups that different services would be welcomed by many. The main alternatives suggested were:-

- day centre access in blocks: Service Users in particular were in favour of this option as they felt day care provided greater social interaction and there was much more opportunity to 'do more'.

- supported holiday breaks for the Service User and their carer together, which would allow an escape from daily routine: the provision of additional support while away would relieve the carer of some of the caring responsibilities
- smaller residential homes would be preferred to larger establishments, where Service Users could get to know the staff and vice versa
- breaks at home were mentioned more often by carers of people with dementia as this alternative did not involve a change of environment which often confused and distressed the Service User
- improved facilities for existing services: needs are currently not being met
- a greater range and variety of activities and things to do for Service Users when in respite
- consideration needs to be given as to whether it is suitable for communal rooms to be used at the same time by Service Users with dementia and those who do not have dementia: conversation/social interaction was mentioned as being difficult by some of those interviewed who do not have dementia

Respite breaks appear to be popular and well managed for individuals under 65, but for older people there are many concerns as stated in the interviews and focus groups. The majority of people over 65 who accessed respite care, whether they had physical disabilities, mental-health related problems, suffered from social isolation or suffered problems related to ageing, felt that improvements could be made, as outlined in the alternative suggestions above.

More variety in the provision and type of respite breaks is recommended, with alternative provision to residential care available. Additionally advice and information on what is available, how to access provision and on personal budgets is required by many.

6. Next Steps

This report will now be sent to the LINK Board for approval and a decision on next steps.

Acknowledgements

Our thanks to the many service users, carers and professionals who took part in this research, including users and personnel from:

- Addison Street Short Break Service
- Alzheimer's Society
- Cedars Day Centre
- Fordley & West Farm Short Breaks Services
- Meadows Day Centre
- North Tyneside Council Adult Social Care
- Shiremoor Day Centre

Appendix 1

Respite Care: Results of interviews and focus groups with service users and carers

All service users interviewed stated that they accessed respite care to give their carer (wife, daughter, son) a break. One person mentioned that they had a week in respite to allow home improvements to be undertaken.

When asked what sort of respite care they accessed, all respondents defined their break as time spent in a residential establishment.

The majority of people interviewed accessed respite care in Dorset House, although other places mentioned were Stanton Lodge, RAF at Rothbury (ex Serviceman) and Beechwood (privately).

For a list of how many places were provided at each establishment see Table 2 (page 3).

How often individuals accessed respite care seemed to vary quite a lot, from once per year to four times per year, dependant on their needs assessment, and the length of each stay varied from a weekend to two weeks, the majority of breaks being for one or two weeks.

The majority of those interviewed accessed their respite breaks via their social worker (care manager), but some said it was arranged by their carer. Many said that greater emphasis should be placed on 'planned' breaks rather than having them arranged at the last minute.

Very few people experienced a waiting list for respite care.

Although some Service Users said they quite liked their time in respite, the majority said 'they put up with it for the sake of their carer.'

Although many of the carers interviewed said their experience of respite care was quite good (from the carer's point of view), a lot of them realised that the person they care for did not enjoy the experience.

Some carers even felt that some living skills (particularly mobility) actually deteriorated following a respite break. This was reiterated by Day Centre managers when a Service User returned to day care after a respite break: it was felt that probably due to staff shortages, Services Users were pushed in a wheelchair rather than encouraged to walk.

When questioned about activities experienced when in respite, many said that there was very little to do: they just sat around. One lady said that if she was lucky there would be ladies of a similar age in at the same time and at least she would have

someone to talk to. Other activities mentioned were knitting, jigsaws and some craftwork.

Comments from an individual accessing RAF respite care were much more positive as trips out were organised, entertainment provided in the evenings and a reasonably priced bar was available.

There was also a negative feel to responses when asked to comment on which parts of respite breaks they enjoy. Most said 'not much', but others did say some of the staff are nice and others enjoyed the art work.

Conversely, the gentleman accessing care through the RAF enjoyed it all, particularly the food, the activities and the company.

Comments about the things they didn't like ranged from the lack of things to do (a very common answer), it not 'being home', 'it leaves me depressed' to 'I would rather stay at day care' 'I'd rather not bother with it', and 'dislike all of it'.

Some of those interviewed who had physical disabilities said that they had difficulty conversing with Service Users suffering from dementia and therefore had little social interaction with others during their break.

When asked what they would change about respite care, many people said they would rather go to day care, attending a centre for 5 days per week, rather than spend the time in a residential setting. This answer was most prevalent from Service Users already attending a Day Centre but a block of one or two weeks at a day centre a few times a year was also suggested by some with no previous experience of day care.

Additional suggestions were that breaks should be more of a 'supported holiday', perhaps together for the Service User and their carer. This was of particular importance to those caring for someone with dementia as very often couples had never spent time apart and would rather have had a break together where the carer could rely on additional support to continue with their caring role (source: Alzheimer's Society).

Some Service Users said that respite care could be improved by having better facilities and more staff but many said that they didn't know how it could be improved.

Many people commented on the cost of respite breaks, often carers saying it was too expensive and they couldn't afford it.

It was felt that there was a lot of confusion about payments, particularly with the onset of personal budgets: most people did not know how this would affect them and it was obvious that a great deal more information and advice was needed.

Appendix 2

Case Studies Depicting Personal Experiences of Accessing Respite Care

Case Study 1: Mrs A

Mrs A is in her 80's and uses a wheelchair: she lives with her daughter and accesses respite care to give her daughter a break. She does not enjoy the time in respite care at all and 'dreads going': she only agrees to it because she understands that her daughter needs some 'time off'.

Mrs A feels that there are not enough staff to look after her properly and they seem unwilling to spend time on social interaction with her.

She feels that there is very little for her to do during her respite care break unless she is fortunate to be there with other ladies in a similar situation who she can talk to.

Asked what would be a preferable option, Mrs A said that she would prefer to attend her Day Centre every day for the week or two she is in respite.

Case Study 2: Mr J (courtesy of The Alzheimer's Society)

Mr J was booked into respite care for a week but asked to go home after 4 days: even though he felt he was letting his wife down, he felt he couldn't take it any longer – he was bored and had no-one to talk to. He commented that staff seemed very busy and didn't have the time to talk to him or give him eye contact. There were no activities available to him.

Mr J has not accessed further respite care because of this experience.

It should be noted that the Case Studies above were similar for the majority of people interviewed; however a very small minority had a different view of respite care as below.

Case Study 3: Mr D

Mr D thoroughly enjoys his respite breaks. As an ex RAF service man he is entitled to access respite care at the RAFA care premises in Rothbury.

Mr D looks forward to these breaks which he views as a holiday for him, while appreciating that it gives his wife a well-deserved break which she uses to visit family or go away with friends, knowing that Mr D will be well cared for and happy.

Mr D commented that the staff are good, the food is always excellent and there is always plenty to do – trips out, evening entertainment, good company etc.

