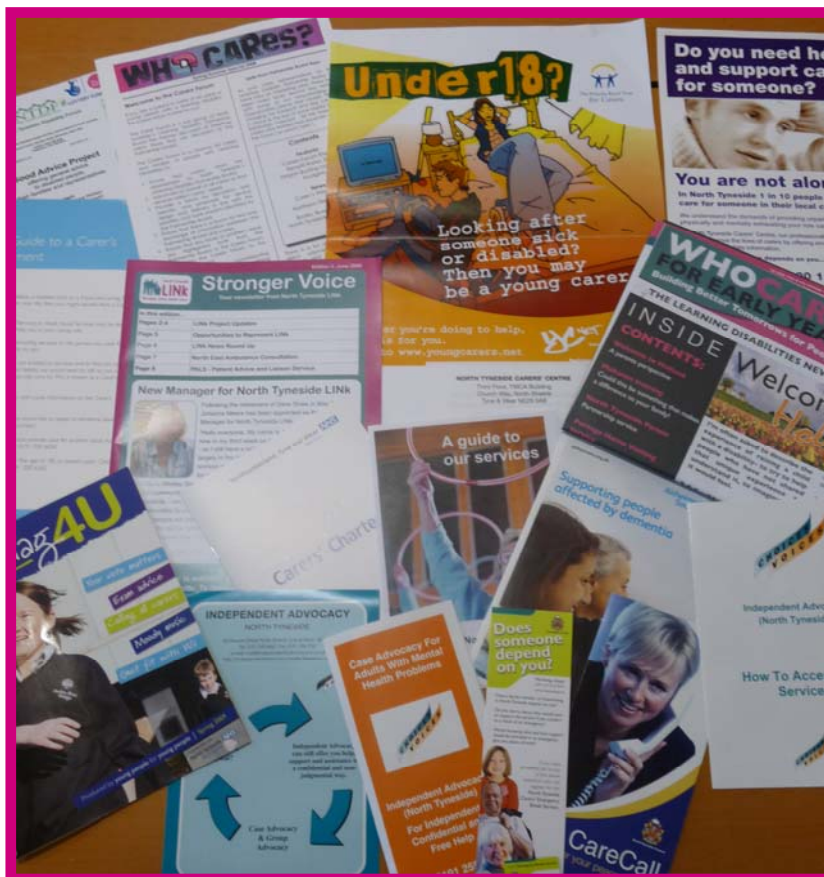




## North Tyneside LINK Report



## Carers' Information Project July 2009

**Link would like to thank the following organisations for their support in this project:**

- The Learning Disabilities Federation
- North Tyneside Carers Centre
- Age Concern North East
- The Alzheimer's Society
- North Tyneside Council
- Northumbria Healthcare NHS
- Independent Advocacy in North Tyneside
- North Tyneside Disability Forum
- The Citizen's Advice Bureau
- And above all, the carers and LINK members who gave their time to take part in focus groups and workshops.

## 1 Introduction

Over the last six months LINK has been gathering the concerns of its members, local residents and local voluntary sector organisations about health and social care. They told us that they are concerned that there is not enough of the right information about health and social care services readily available.

During May and June 2009 LINK has been investigating what information is available for carers in North Tyneside. During this period LINK has undertaken a scoping exercise to get a better understanding of what information is available, and whether this information meets the needs and expectations of service users.

LINK chose to focus this study on carers as they represent a diverse group of individuals who access a wide range of health and social care services either for themselves or on behalf of the person that they care for. Recognition of carers was also a topic discussed in some depth at the LINK launch events. LINK approached North Tyneside Carers Centre and The Learning Disabilities Federation for support with this project.

LINK met with three groups of local carers to find out what their experiences of accessing information was like, and to ask what, if anything, could be improved. As well as this, LINK has approached several information providers from statutory services and the voluntary sector to find out what information they provide for carers, and whether it meets carers' needs.

## 2 Background

In January and February this year LINK held four launch events. The purpose of these events was to engage with residents of North Tyneside and to identify, through voting, what their health and social care concerns and priorities are. Several issues scored highly in the voting exercise and access to information was identified as a cross cutting theme. Issues in this topic ranged from a lack of information and a lack of accessible information to too much information, use of jargon and not being given the right information at the right time.

## 3 Summary of findings

LINK met with three groups of carers, including a group of young carers. We met with these groups at The Learning Disabilities Federation (LDF) and North Tyneside Carers Centre. This is a summary of what they told us along with feedback from the LINK launch events.

### 3.1 Where carers access information

Carers told us that they access information from a variety of sources.

**Websites:** as well as using internet search engines such as Google to find information relating to carers' needs or specific health conditions, carers told us that they use [www.nhs.co.uk](http://www.nhs.co.uk), [www.carers.org](http://www.carers.org), [www.ldfnt.org.uk](http://www.ldfnt.org.uk), [www.barnardos.org.uk](http://www.barnardos.org.uk) and some local GP websites.

**Media:** carers told us that they find out information relating to health conditions (of the people that they care for) from TV, whether it be adverts such as the recent Stroke or British Heart Foundation campaign, to the Action for Children adverts and storylines (e.g. carers storyline in Eastenders) and documentaries (e.g. recent Stephen Fry documentary looking at mental health conditions). The young carers group had also spotted a Princess Royal Trust Carers Centre poster in the background on Eastenders.

**Statutory Services:** we were told that a lot of carers rely on their social worker to pass on information, or to refer them to local voluntary and community sector (VCS) services. Some carers had been referred to the Carers Centre by hospital staff and young carers are often referred to the centre via Children's Services. For those caring for people with dementia, the Memory Clinic also runs a six-week course for carers, which offers a variety of information including financial and legal advice. Some carers said that they pick up leaflets in their GP surgery, which encouraged them to look up further information:

***“Made me Google for more information”***

**– Young Carer**

***“Read one on thyroid conditions and I called up for further information.”***

**– Young Carer**

**Voluntary and Community Sector (VCS) services:** carers told us that they get a lot of information from the VCS. Not surprisingly LDF and the Carers Centre were cited. Other organisations that were mentioned as being useful sources of information were Age Concern North Tyneside, The Alzheimer's Society and (for younger carers) Barnardos. Some carers were also involved with VCS groups in Newcastle. Services that carers received from VCS organisations included groups and forums; meetings and events

(Carers Week) where different carer related information is presented and where carers can exchange information and support one another; carers breaks services; social events and outings, staff who will look up any information that you need; regular newsletters with information on local services and on national carers issues.

***“If you go to one thing and chat to people it snowballs and you can get masses of information.”***

**– Carer**

**Other:** carers told us that they pick up leaflets at various places (GPs, VCS organisations, libraries). Young carers found schools (teachers and learning mentors) and Connexions (personal advisors and leaflets) particularly useful sources of information. Most carers we spoke to said that they picked up bits and pieces of information just chatting to people, whether it be friends, colleagues or other carers. Parent carers also said that they got information from their children’s schools, although this wasn’t the case if their child was in mainstream education.

## 3.2 Barriers

Carers shared with us a variety of barriers that they have come up against when trying to access information. Carers told us that they feel that they are dependant on professionals (social workers, health staff and VCS staff) to give them the information that they need.

**Professionals - Local Authority:** some carers told us that they had experienced a lack of communication and coordination between staff within the local authority. This meant that they often had to repeat the same information several times and did not like having to fill out lots forms with the same personal information (for financial support). Carers also told us that they felt that when the Council consults with them, the decisions have often already been made and their voice isn’t really heard.

Some carers (often parent carers and working carers) felt that if they do not have a social worker then they are left to get on with it without any support or information on carers’ support services what so ever. We were told that the information people received often depended on the individual’s social worker; some felt that they had excellent social workers who gave lots of helpful information and referrals to VCS, others felt that they are not getting much information, and because they don’t know what is available, they don’t know what to ask for.

Carers also told us of situations where they had rang a council phone number for some specific information, and they would be passed around staff and departments without anyone taking responsibility for responding to the enquiry.

There were particular issues regarding social work staff moving offices from North Shields to Longbenton – carers could not get though to who they needed to talk to and no one would take messages at the end of the phone

at the Oxford Centre in Longbenton. There was no voicemail option and people found that their emails were not being responded to.

**Professionals – Health:** carers told us that they had experienced several problems accessing information from health services. As with social workers, carers' experiences of receiving helpful information from their GP varied with some saying they had excellent GPs who could give them local information, and others receiving no carer related support or information.

One young carer told us that when looking for a dentist she could not find anything on NHS website and so called NHS Direct. They gave her the number of a local dentist who they told her was taking on NHS clients. However, when she rang, the dentist said they were not taking people on. The information she had been given was wrong and left her back at square one.

Carers told us of particular concerns regarding communication with health professionals regarding the person that they care for.

***“The information that they pass between (health) professionals isn't always accurate, but they won't listen to the carer.”***  
***– Carer of someone with a mental health condition***

There were concerns regarding patient information in cases involving mental health issues. Carers (in these cases family members/next of kin) were denied information regarding the health of the person that they care for. This led to worries about the carer's safety if they are unaware of the cared for person's state of mind. Carers in these situations were told that they could not have information patient confidentiality.

Carers of people with mental health conditions also told us that the hospitals did not keep them up to date when the patients were being moved between wards or hospitals and that they felt they constantly had to chase staff to find out what was going on.

In all these cases carers were frustrated as they felt that they have valuable information regarding the person that they care for that professionals were not interested in hearing.

**Websites:** although many carers do use websites, there was some concern that information is not always up to date and that some websites (in particular the NHS and North Tyneside Council) are hard to navigate. One young carer could not find what she was looking for on the Council website (a school address) and had to get help from her teacher.

**Media:** problems that carers experienced included: information in the local press is often too late (i.e. meetings happening on the Friday advertised on the Thursday, carers need longer than that to organise carer relief), the local press (including Up Close and News Guardian) do not reach all households in North Tyneside, and information advertised (such as phone numbers) is often out of date.

**Working Carers:** working carers had particular problems accessing information. This was often because they did not have the time to attend groups and forums or to research what is going on locally. The working carers that we spoke to also did not have social workers, who are often the link to local information and services. Working carers told us that they felt they had been left to get on with it alone and that no one was trying to communicate with them.

**VCS:** carers we spoke to access a large amount of information and support from the VCS, but there were concerns about lack of funding and that without sufficient funding good services could be withdrawn and then where would carers go for information and support?

**Mental Health:** carers of people with mental health problems felt that there was much less support available for them locally. One carer had to travel to Newcastle to attend a mental health carer support group and it was pointed out that there are much fewer VCS organisations supporting people with mental health problems and their carers. It was felt that because of the stigma attached to mental health problems, there is much less information readily available.

**Taking Part:** it was felt that if you were unable to take part in local VCS groups (due to caring responsibilities or employment) then you would miss out on a lot of information. In particular, people did not know how you would find out about respite. Carers also said that not enough happens for carers in the evening; all the groups and forums take place during the day and always in the same locations. Carers wanted more people to attend meetings and forums who could bring different experiences and information. It was also suggested that meetings must have specific agendas so that carers know that it will be of interest or help to them before they make alternative caring arrangements.

The young carers that we spoke to had not experienced many barriers to accessing information. They said that they would ask a learning mentor, Carers Centre or Barnardos staff, who had always been able to provide the information that they were looking for. None of the young carers had seen the North Tyneside Carers Guide.

### 3.3 What was good?

LINK met with several local information providers, who gave us examples of the information that they produce. We showed this information to carers and asked them to tell us which bits they liked. (The Carers Centre was rebranding their information at this time).

**Young Carers:** young carers particularly liked the Connexions booklet; 'Do You Care?' and felt that the mixture of personal stories, information, and bold print was good for the target age group. Young carers liked leaflets and booklets to be brightly coloured. They said that the design would have to be eye catching to make them pick up a leaflet in a GP practice. They told us

that large print text was the best option, without too much information, but contact details to get further information (including a website address). Other leaflets the young carers liked were Streetwise leaflets for the bright and bold design, and the NSPCC leaflet for the contact information.

**Content:** carers wanted information to be relevant locally and it was essential that information must be current and not out of date. Good information should also have contact details, not just websites and emails as not all people have internet access. Content should also be easy to read and not use long medical terms. Carers wanted leaflets to be brief and straight to the point.

**Layout:** Carers wanted leaflets to be bright and colourful with a simple layout. Helpful phone numbers should stand out.

**Where you can get it from:** Carers told us that they like to attend events where they can access lots of information in one place. The Carers Centre roof top party during Carers Week was mentioned several times as was the 'Daslne' (database of children with Autism Spectrum Disorder Living in the North East) conference. Some carers received information from the LDF Carers Forum and other carers meetings and some carers received regular newsletters from LDF and the Carers Centre.

**Good Examples:** The carers that we talked to particularly liked

- 'Who Cares?' – LDF
- Age Concern North Tyneside information book
- Carer's break service leaflet – North Tyneside Council (?)

Carers felt that there was a lot of information out there, and on the whole it was good information, but it needs to be more readily available.

### 3.4 What was bad?

Things that carers found frustrating with information included;

- Badly produced newsletters
- Out of date information
- Websites that don't work
- Leaflets that are too 'wordy'/difficult to understand
- The fact that the same images are used for different purposes
- Too much information at once
- Incorrect information (especially dates)
- Reliance on internet – not everyone has access
- When leaflets encourage you to apply for a service/grant that you are not eligible for. The criteria should be made clear, to save carers from wasting their time and effort.

## 4 Provision of local information

During this study LINK met with or gathered information from:

Age Concern North Tyneside  
North Tyneside Carers Centre  
The Learning Disabilities Federation  
The Alzheimer's Society  
Independent Advocacy in North Tyneside  
North Tyneside Disability Forum  
The Citizen's Advice Bureau  
North Tyneside Council Service User and Carer Engagement Officer  
Northumbria Healthcare Patient Information Manager  
Connexions Tyne and Wear

A brief summary of how these organisations provide information for carers is attached at Appendix 1.

### 4.1 What are statutory organisations currently doing?

#### **Northumbria Healthcare NHS Foundation Trust**

- Is currently engaging LINK members and Foundation Trust members on the development of an Information Centre in North Tyneside General Hospital.
- Has a Readers' Panel and a Patient Information Advisory Group which includes LINK members and Foundation Trust members who can give feedback on information produced by the Trust.
- Is reviewing the effectiveness of the general information it gives to patients about particular health conditions and treatments (which could be useful for carers too) currently, and this includes research with patients about their needs and expectations. It is also reviewing what further it could do to provide a more holistic approach to information, that would include all the services it offers patients and some of the services that others offer, (for example information about benefits), in conjunction with the local authority, voluntary organisations and others so that patients can get more and improved information in one place. North Tyneside LINK is involved in this programme of work although it is still at early stage. The printed information the Trust provides patients is just one aspect of improving communications with patients; it has have recently improved and speeded up consultants reports for GPs and patients, and has also run award winning programmes for people who need more information and support, such as those run by the stroke service.

#### **North Tyneside Council**

- Within North Tyneside Council carers are being invited to make presentations to directors to raise awareness of carers' issues. It is hoped that this will be rolled out to other council staff.

- North Tyneside Council's Adult Social Care Plan 2009-11 has three priorities. One of these priorities is:

*“The development of improved advice and information services which all citizens can access regardless of ability or eligibility”*

## 4.2 What LINK is doing?

- Membership – LINK is continuing to develop its membership. As a member of the network you will receive information about local services, groups and events in our newsletter Stronger Voice and our regular email bulletins. As a member you can also contribute to our newsletter and on our website. Members are also encouraged to share their concerns, experiences and suggestions for local health and social care services. Where themes in issues emerge LINK will work with members to bring them to the attention of service providers and commissioners and involve members in developing solutions to problems.
- Website – we update our website regularly with local health and social care information, we are also developing a discussion board function that will allow members to share information with one another.
- Member representatives – LINK has been invited to sit on various groups and boards throughout North Tyneside and the region. These provide excellent opportunities to share information, which we can then feedback to our members.
- Annual Event – LINK will be holding an annual event. This will include a market place of local health and social care services, both statutory and voluntary organisations, based on recommendations from our members.

## 5 Recommendations and Suggestions for Improvement

It is clear that there is a lot of good quality information available for carers (for carers services, services for the cared for person and on health conditions). However, unless you are already involved with local organisations, or have a well informed GP or social worker, it appears that carers are still missing out on information that could be beneficial to them.

Carers have little time available due to their caring roles and therefore it is important that information that is relevant to them is very easily accessible and that all carers know where to go to access information.

North Tyneside LINK would like providers of information to consider carers suggestions for improving information and would appreciate feedback on any current plans to improve information services.

Better communication between all service providers (statutory, voluntary and private) would give staff the necessary knowledge to refer carers to helpful services and local groups.

## 5.1 Suggestions for improvement

The carers we spoke to both at focus groups and at the LINK launch events had lots of ideas about how information providers could make their information more accessible.

**Events:** The carers we spoke to wanted more 'market place' events where information and service providers are brought together in one venue, with staff available to answer questions and explain things. These events need to be widely publicised to ensure that all carers (including working carers and those without social workers) are aware of them. Events should also take place at various times and in a variety of locations.

**Communication:** Carers felt that every mode of communication should be used to ensure that no carers were missed out including leaflets, local press, phone numbers, emails, websites and addresses. One suggestion was that local services for carers could be advertised on local products (i.e. the sides of milk cartons). Carers also wanted more punchy, straight to the point posters telling them what they are entitled to (benefits, respite etc). They said that charity shops could have more information in them – the bigger, well funded ones like Mind have all the information leaflets in the shop, small ones don't, but they would be easily accessible, you would recognise where to go for leaflets.

Another suggestion was for carers' organisations to come together to advertise their services jointly. Carers also wanted to see the VCS working together to share aims, good practice and to improve communication.

It was also felt that work places should be targeted with information for carers. The council should target larger employers in the borough to advertise carers' services to staff. Other suggestions included sending out information with council tax bills (as this would reach every house in the borough), and the Council taking responsibility for contacting carers on an annual basis to offer services or information and to ensure that they are still coping.

It was suggested that information for carers could be given to people using transport services, who could pass it on to their carer.

More information could be given out when the cared for person is diagnosed, information on the patient's condition and on carers' services.

To improve GPs knowledge of VCS services, it was suggested that VCS organisation be invited to GP staff meetings to share this information.

It was felt that if carers' information was more readily available in the public domain then carers would be more forthcoming when expressing their needs and sharing their experiences. Carers wanted to have more access to other carers to share experiences and to offer support and advice.

**Media:** The carers we spoke to had several suggestions for advertising. Local services and groups should be advertised on the buses and on the Metro. The young carers suggested that leaflets should be available from Metro stations on a variety of subjects. They felt that picking up a leaflet in a public place was more anonymous and therefore less embarrassing than picking up leaflets at school. It was also suggested that carers groups and services were advertised more frequently in local newspapers.

They said that more information on TV was a good way to raise awareness and that this could be in the form of adverts or documentaries, both on caring and on different health conditions. It was also suggested that the Community Links programme that gave information on local services, events and groups should be reinstated.

Young carers told us that they get council magazines distributed through schools. They suggested that more health and carer information could be put in these magazines.

**North Tyneside Council:** Carers suggested that as soon as you come into the social care system you should be given more information on all (not just Council) local services. Although some carers shared positive experiences using libraries, it was felt that there should be a lot more carer and health related information available at libraries, both in books and leaflets. Carers also thought that there could be more information and contact details for services and groups in Up Close magazine and on public notice boards in council and VCS venues.

**Health Professionals:** across the board, carers told us that they wanted more information from health professionals; this includes regular updates on the condition of the person that they care for. They also felt that GPs could give more information about local services and groups (some had a good experience of this, others did not). Carers also wanted more information on services available for patients once they have left hospital.

## 6 Next Steps

This report will be sent to North Tyneside Council, North Tyneside PCT and Northumberland Healthcare NHS and will be circulated within the voluntary sector in order for information providers to consider carers' recommendations in the report.

LINK's work on information does not end here. As already noted, information is a cross cutting theme that emerges in many issues report to LINK. At present LINK is looking at information in the following areas:

- Young people's health services – Young people have told us that there is not enough information on local health care services aimed at younger people. LINK is working with a group of young people to design information leaflets and posters and to develop a survey to capture views of more young people in north Tyneside.

- Personalisation of adult social care and personal budgets – LINK has a working group that acts as a critical friend to North Tyneside Council in its development of the personalisation agenda. This group will be looking at information provided by North Tyneside Council and A4E (support agency) to service users to ensure that it is user friendly and widely available and accessible.
- Counselling services – LINK commissioned the Community and Health Care Forum to produce a report on the provision of counselling services in North Tyneside. This report included a guide to voluntary sector counselling services, which will be sent to GP surgeries and made available more widely.
- LINK is also working with Northumbria NHS to look at improving information and communication between staff, patients and carers during the hospital discharge process.

If you would like to get involved in any of LINK's work regarding information, please contact the LINK Team (contact details at the end of the document.)

## Appendix 1

### Information Providers

**Age Concern North Tyneside** – Age Concern North Tyneside produce a variety of information leaflets about the services they offer including advice and guidance, social activities and volunteering opportunities. Most carer related queries and information comes through the advice and guidance service. Age Concern leaflets are available in their North Shields based centre as well as across North Tyneside in community venues. Leaflets have a date on them so that people know how current they are.

Some leaflets are also available in GP practices. The Age Concern 50+ Information file has also been given to GP practices in North Shields and Whitley Bay and to libraries.

In order to ensure that the information is user friendly, Age Concern asks its members to evaluate their information leaflets.

Many people find out about Age Concern's services through word of mouth. Through face to face support and advice, Age Concern staff are able to identify unrecognised carers and offer specific information regarding their caring role. Age Concern estimates that 40% of enquiries to their information and advice centre are carers.

Age Concern North Tyneside are also informing other local organisations of their services through 'Speed Meetings' and have a volunteer on the North Tyneside library bus, who provides information to people accessing the service. Information is also available at local authority customer service centres.

**North Tyneside Carers Centre** – The Carers Centre have recently rebranded their information and it was not available at the beginning of this project. However, the Carers Centre makes its leaflets available at community venues across North Tyneside, in North Tyneside General Hospital, and in local GP surgeries practices and sends out a regular newsletter to its service users.

The Centre's young carers' service is also advertised in Mag4U, a council publication that is available in schools across the borough.

**The Learning Disabilities Federation** sends its newsletter to 2000 contacts in North Tyneside. This includes carers who are registered with LDF, libraries, day services and places where people with disabilities and carers meet such as the Carers Centre and the Rising Sun. Health information from LDF, which is developed with people with learning disabilities, is sent out to local GPs as well as voluntary sector organisations and residential homes for people with learning disabilities.

LDF also have regular press releases in the News Guardian (free local paper).

**The Alzheimer's Society's** office is in the centre of North Shields. A wide variety of information in the form of leaflets, books and one to ones with staff is available. Leaflets are also available in local GP practices and are regularly updated and replenished.

Locally the Alzheimer's Society provides information on a range of services. Its information pack was developed with carers and includes information on services and practical help. The Council's social care team also have access to the Alzheimer's Society's care homes pack and general information is available at the Memory Clinic. Staff also refer carers to the Carers Centre and Age Concern North Tyneside.

All information that the Alzheimer's Society produces is regularly reviewed by carers.

There is also a national helpline and information specifically for carers within the Alzheimer's Society's website and the national charity has developed a carers handbook.

**Independent Advocacy** – Independent Advocacy recently updated its information leaflets. Leaflets are available on wards at North Tyneside General Hospital and through various support groups in North Tyneside. Service users are always consulted when leaflets and posters are being designed.

Independent Advocacy make referrals to the Carers Centre for carer specific issues.

**North Tyneside Disability Forum** – NTDF has a Good Advice Project and a resource room that is available on an appointment basis and has a lot of information on other local services (voluntary and statutory sector). NTDF also signpost people to other services. In the case of carers, NTDF often signpost to the Carers Centre.

The Good Advice Project will also be holding a providers event in July, which aims to improve communication between providers of information and advice across North Tyneside and to give the opportunity for organisations to work collaboratively.

**The Citizen's Advice Bureau (North Shields office)** receives a lot of queries from carers. The information they provide is on a one to one basis rather than in leaflets. CAB often deal with financial and legal queries related to caring. Where carers need further advice or support CAB refer to the Carers Centre.

**Connexions Tyne and Wear** – Connexions in North Tyneside have a shop in North Shields where young people can drop in or make an appointment to see a personal advisor. Staff can advise on training and career options as well as offer support for social issues and benefits and refer to other support organisations. As well as talking to staff a variety of information is available in the waiting area including leaflets on young carers.

Connexions leaflets and staff can also be accessed in schools and colleges.

**North Tyneside Council** provides information to carers on carers' assessment and emergency breaks as well as the producing the Carer's Guide, which was developed in 2008. These leaflets are available in frontline council services such as libraries, joint service centres and community centres.

**Northumbria Healthcare Trust** produces a variety of information on health services that it provides including leaflets and booklets explaining what patients and carers need to consider when staying in and leaving hospital.

**North Tyneside Local Involvement Network**  
**The Shiremoor Centre, Earsdon Road**  
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