The Leeds Early Intervention in Psychosis Service.

To have ambitious hopes or plans; strive towards a higher goal; rise upwards
Service Information pack for aspire

You will be supported by one of our area teams. You will have a designated aspire worker who will work with you to find and organise the best type of support that works for you.

your team is the .................. team.

your aspire worker is:

................................................

................................................

mobile number

................................................

................................................

People usually stay with aspire for 3 years. We suggest you keep the booklet throughout contact with aspire as you may want to access different chapters at different points.

Contacting us

aspire, Community Links, Bank House  150 Roundhay Road, LS8 5LJ
Open Monday to Friday 9-6pm.

Telephone: 0113 2009170
The office is open from 9am to 6pm Monday - Friday. At other times there may be someone to receive your call alternatively try your worker’s mobile.

For further information please visit our website:
www.aspireleeds.com

Follow us on Twitter @commlinksnorth
Find us on Facebook
www.facebook.com/aspireCL
What’s in this booklet?

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What is psychosis?
What is psychosis?

The signs of psychosis are many and varied and can change over time.

**Experiences of psychosis may include:**

- Hearing voices that no one else hears, seeing, smelling or tasting things that aren’t there.
- Believing that others can influence their thoughts, or that they can influence the thoughts of others.
- Believing that they are being watched, followed or persecuted by others.
- Feeling that their thoughts have sped up or slowed down.
- Thinking in a confused and disorganised way.

**Additional early signs of psychosis may include:**

- Withdrawal and loss of interest in usual activities.
- Loss of energy or motivation.
- Problems with memory and concentration.
- Deterioration in work or study.
- Lack of emotional response or inappropriate emotional display.
- Sleep or appetite disturbances.
- Unusual ideas or behaviours.
- Feeling “changed” in some way.

**What if we are not sure?**

All the signs that we have described may just be a reaction to a one off stressful event. If the experiences carry on, it is important to get things checked out as quickly as possible. Early treatment of psychosis can make it much easier to deal with. If we are not sure we call it ‘diagnostic uncertainty’ or ‘extended assessment’. This means we want to find out a bit more about what is going on for that person. The young person is supported by the service for a short period, may be a few months.

When we take a person onto our caseload it means they will be given an individual worker, known as a Care Coordinator, who will be their personal contact and a source of support for the time they are with us. They will be able to come to aspire activities which we hold at least once a week on a Saturday and other days; including pool, bowling, meals for the over 25’s, walks and cinema.

We can complete additional assessments with the individual and possibly consult with friends and family to establish whether they are having experiences of psychosis. If we think
the person is having psychotic experiences they will probably stay with aspire for a period of three years from the date of the initial assessment.

If we think the individual has other difficulties we will recommend other services for them to access. We will usually make a referral to other services.

**Why is early intervention important?**

Early intervention is used across England and Wales because the research shows it helps prevent psychotic experiences developing into something more serious and long-term. The process of recovery is different for each individual. Some people have a single mental health crisis which doesn’t return. Other people might have some experiences that continue to cause them distress but which can become easier to manage with time and experience.

Early intervention uses a **bio-psycho-social model** that combines:

- psychological approaches
- low dose medication
- working with the family
- maintaining social activities
- links with education and employment.
Research has shown that treating psychosis as an illness that is cured only by the use of medication is not very effective. The rate of relapse is often high, and there are serious health concerns with the long term use of anti-psychotic medication.

**What causes psychosis?**

This is a difficult question to answer as there are very different views about this. Here are some of the most commonly discussed causes:

- Traumatic life experiences
- Genetic vulnerability
- Using certain drugs
- Spiritual experiences

aspire understands psychosis as an expression of something for which there has been no language. In other words, psychosis comes about when things happen in our lives that are
difficult to understand and explain, or when there is no way of talking about things with other people. The triggers may be obviously traumatic, such as abuse and bereavement, or they may seem relatively minor. It can depend on how the experience is understood by the individual.

Hereditary factors may play a part for that an individual they may have a genetic vulnerability towards mental distress. Some psychotic experiences seem to be directly linked to heavy drug use, others may be triggered by it but continue after the drug is no longer used.

**Getting help early:**

aspire aims to identify and support those experiencing psychosis as early as possible. This is because research evidence shows that the sooner a person receives support, there is an increased likelihood of long-term recovery.
Introduction to aspire
Introduction to aspire

aspire is a Community Links service funded by the NHS. It provides specialist support for young people aged between 14 years to 35 years with early or suspected onset psychosis. We are the Leeds Early Intervention in Psychosis Service. We can work with individuals and their families, partners and friends for up to 3 years.

Our principles and values:

In three words, the service’s principles and values are ENGAGEMENT, HOPE and RECOVERY.

aspire’s aims:

- Be young person centred
- Support people to find their own level of recovery
- Foster hope about the person’s future
- Show that people who have experienced or are experiencing psychosis can lead ordinary lives in their community
- Prioritise service user choice
- Be sensitive and appropriate to sexuality, gender, ethnicity and culture, age, disability, economic circumstances etc.
- Family and friends contribute greatly to support for many people
- Learn from the experiences of our service users
- Engage with people on their terms
- Take positive therapeutic risks
- Team working, and team responsibility to support a key worker approach
- Collaborate with service users, carers and family
- Take an evidence-based practice
- Work in a bio-psycho-social model
- Contribute to the research base
- Learn from experience
- Deliver the service at the most appropriate location and environment
- Find and provide what is right for each client as an individual

We aim to reduce the stigma which surrounds people who have psychosis. To do this we:
- Value people as human beings
- Are accepting and understanding
- Believe in people, their abilities and their potential.
- Accept that failure and setbacks can be part of the recovery process
How aspire will support you...

Now aspire is supporting you, you will be allocated a worker who will be your Care Programme coordinator and you will be allocated to a particular team.

At aspire we use a team approach which means other people may be involved with supporting you during your time at aspire. You can discuss what would be helpful for you with your worker. The teams are split into different colours, and people have different job titles. The team structure is shown in the diagram on page 15. Each colour team has a mixture of:

- Senior Early Intervention in Psychosis Practitioners
- Early Intervention in Psychosis Practitioners
- Early Intervention in Psychosis Recovery Workers

Your named worker may change during your time with aspire. Some of the other people you may meet have particular specialisms:

- Family therapist
- Employment specialist
- Drama therapist
- Support Time and Recovery worker
- Mental health nurses
- Psychologist
- Psychiatrist
- Volunteer link worker

You may also want to work with or seek advice from one of our workers with specialist roles. These are:

- Black African and Caribbean worker
- South Asian Worker
- Lesbian, Gay, Bisexual and Trans* worker

They can do direct work with you, either as your allocated aspire worker or you can arrange to see them for short term support on a specific issue. They can also offer support and advice to family and friends and aspire colleagues.
The structure of our team:

- Aspire manager
  - Team Leader
    - Yellow Team
      - Senior Practitioners
    - Orange Team
      - Practitioners
    - Green Team
      - Recovery Workers
    - Blue Team
Care Programme Approach

Once you are supported by aspire you are receiving support from a specialist mental health service and we are responsible for planning and providing a plan for your care. The formal term for this is Care Programme Approach (CPA). The aim is to involve you, your family and sometimes other services in identifying your needs and establishing how we can work together to reach your goals. This will include written care plans, review meetings and a range of assessments throughout your time at aspire.

Your aspire worker will act as your CPA coordinator and will be responsible for managing your support in working towards your recovery. aspire will help you identify your goals, steps to achieve them and record your progress.

Your aspire worker will also record information about any relevant risk issues, and where required, plan support to address these. We do this using a FACE risk assessment. This includes a checklist of possible risk issues related to your own or other’s safety and a specific plan where risk issues are identified.

We encourage you to be involved and informed throughout your time at aspire, so please ask your worker for further information.
How we work with friends and family
What can we do for family, friends, carers?

At aspire, families and friends are considered to be the most important people in your life. We know that the research says that when the family is involved the outcome is improved.

Someone supporting you with your psychosis may be described as a “carer”. A family member, close friend or partner may be identified as a carer and mental health services have recognised that carers need information and support as well. Here are some of the things aspire can offer your friends and family:

- The aspire Family and Friends information booklet
- The Family link worker can offer an opportunity to hear their views and ideas about what is happening.
- Information and support can be given to them about how best to help you.
- Support for their experiences as a carer.
- Family and Friends Forum – an opportunity for them to meet others in a similar situations.
- Family support work and family therapy – Planned sessions with a family therapist, family members and yourself.
- Being involved in reviews of your care.
- Advice regarding benefits that they may be entitled to.
• Specific information for brothers and sisters.
• An assessment of their needs as a Carer by the mental health specialist Carers Team -Tel 0113 2954445
• Young people whose parents have mental health difficulties can get help from the Willows.

We encourage all the young people we work with to support us to contact the friends and family that you identify as being very involved in their life, so they get the opportunity to receive any of the above support.

One way that will help them get the information about aspire is to go on the family and friends information data base, which will help us ensure they have access to information about events and activities that they are invited to attend. They can send us contact details by completing the contact form at the end of this pack, please help us by making sure they see this section of this pack.

All names and contact details will be kept confidential within the aspire service
Social recovery
What is Social Recovery?

Social recovery is a term used to describe the improvement of a person’s social and occupational progress and their feelings about their personal identity.

Social recovery might involve getting back into work, education or volunteering, but can also include other fun and creative ways to meet people, increase confidence and make the most of your spare time. Another important aspect of social recovery can be connecting or reconnecting with friends, family, peers and your community. This might involve you developing the skills and confidence to meet new people and expanding your social life.

It is recognised that social recovery is a crucial aspect of getting and staying well following a period of mental health difficulty. Studies have shown that taking part in meaningful activities can aid recovery. Evidence tells us that such activities can:

- Provide opportunities for enjoyment and fun
- Prevent relapse
- Boost self esteem
- Increase motivation
- Reduce isolation
- Promote health & wellbeing
- Help you make friends
• Combat stigma
• Develop strengths and skills
• Reduce contact with mental health services
• Help you feel normal again

During your time at aspire your aspire worker will help you to identify which social recovery goals are important to you and how we can work together to achieve these. Different ways we can support you with this include:

• One on one support with your aspire worker.
• Linking into one of aspire’s social groups and activities.
• Being referred to our employment specialist.
• Receiving support from an aspire volunteer.

We encourage you to make use of what is available in the community, e.g.
• Sports centres
• Cinema
• Faith centres
• Community arts projects
• Colleges
• Social groups
- Specific hobby and interest groups
- Social venues, e.g. cafés, restaurants and bars.

For some, starting to socialise again is a big step and, for those people, aspire organises a range of activities and will support people to take part and help develop their confidence. Types of activities we run vary throughout the year, but may include:

- Pool drop in at a local bar
- Football at local leisure centres
- Service User Action Afternoon
- Women’s Group
- Badminton
- Tennis
- Walks and nature trails
- Monthly Saturday activities, e.g. visits to the cinema, ten pin bowling, day trips, places of interest, shopping etc.
- Friends and family forums
- Creative writing group
- Art workshops
- Residential activities

Please ask your aspire worker for an up to date activity programme or look at our website.
Quotes from aspire service users

‘I was able to share my experiences with other people who have been affected by psychosis’

‘Gave me things to do, feel like I’ve got support’

‘aspire has helped me in expressing my feelings and being able to talk about them when at times it was hard to do’

‘The aspire team have really helped me, their support has made me feel less alone and less scared’
Employment

At aspire we have an Employment Specialist. They can help you and offer advice, guidance and support that will increase your chances of finding or keeping employment.

You may want to see the Employment Specialist if you are looking for work and would like some help securing the right job, or if the thought of returning to work is daunting and health concerns are holding you back, or you are in work but think that your job is at risk due to your health. Referrals can be made by your aspire worker, however if you are unsure about whether you are ready for employment then a pre-referral information meeting can be arranged to help you decided if you are ready.

We believe everyone’s journey into work is unique and therefore help is individually tailored to your needs. Working with you and your aspire worker, the Employment Specialist will help you with your journey into employment.
Some of the ways that the employment specialist can help you are:

- Information and advice on choosing what career you would like
- Help producing or updating your CV
- Identifying training needs
- Improve your job search skills and access to Work Place Leeds job club
- Advice and help to complete application forms
- Voluntary experience and work placements
- Help to prepare for an interview
- In-work support
- Keeping you motivated with your search for work
**aspire Volunteers**

Volunteers play an important role within the service in helping to support the activities that we run for clients. You might come into contact with a volunteer if you choose to take part in one of our group activities such as women’s group, action afternoon, pool, walking group or football.

A volunteer might also meet with you on a one to one basis to help you work towards a personal goal relating to your recovery. This could be to increase your confidence around:

- Meeting new people
- Attending courses/classes
- Starting a new hobby

If you feel you would be interested, your aspire worker can refer you to the volunteer link worker. You will then be consulted to find out what sort of contact might be of benefit to you and we will try to match you with a suitable volunteer.

Some of our volunteers will have had personal experience of mental health problems and some may be ex-service users of aspire themselves and feel able to support others. Volunteering with aspire may be something you wish to consider in the future once you are no longer using the service. If so, you can ask to be referred to the volunteer link worker who will be able to provide you with more information about the opportunities available.
Psychological work
What is Psychological work?

- A psychological approach helps people by talking.

- The aim is to get a better understanding of what’s going on and work out a way forward.

- As well as talking, you might do other things, such as drawing diagrams or pictures, or planning ‘experiments’ to test out your fears and build your confidence.

- The most important thing is building up a trusting relationship so that you feel comfortable to be open and honest.

- You may prefer to do some of this work with a member of the aspire team who you trust. Alternatively, it might be helpful to see a specialist psychologist/therapist, who has had extra training and who can offer more regular and focussed sessions.
What will we talk about?

- It is up to you and the therapist/worker to decide the things you should focus on. The therapist/worker will never push you to talk about things if you don’t want to. Sometimes people talk about things from the past that are affecting their lives now. Other people may prefer to keep things in the ‘here-and-now’.

- Specific psychology sessions can help you with any issue that is making you feel distressed. Some common ones are:
  - Hearing voices that make you feel bad
  - Thoughts & beliefs that other people don’t understand
  - Grief/loss
  - Confidence/self-esteem
  - Relationship problems
  - Traumatic experiences
  - Problems with alcohol or drugs

- Many people who experience psychosis have lived through some kind of trauma. Feeling frightened, vulnerable or suspicious of others is understandable after living through trauma.
**Where would we meet?**

- You can do psychological work wherever feels best for you. The most important thing is that you feel safe and free from distractions. Sometimes it helps to meet at your home, sometimes it is better to come to somewhere separate from your everyday life, such as our base at Bank House, or your GP surgery.

**How long would it last?**

- The number of sessions you have depends on what you and your therapist decide. This can range from just a one-off meeting up to a year of regular sessions.
Medication
The aim of this chapter

To help you focus on the choices you can make for managing your symptoms and difficulties. Using this information and working together with your doctor or care co-ordinator will hopefully ensure that you receive the treatment that is most suited to you. Although the focus of this information is mainly on medication, there are other important options that will form part of your treatment plan. These include psychological therapies as well as support for you and your family.

Treatment with Medication

When someone is experiencing very distressing symptoms and feels unable to cope, they may be prescribed medicine. The idea of taking medication may be scary but the aim is to find the lowest dose that works. Remember, other types of treatment are also used, but this section is mainly about anti-psychotic medication.
Medicines may be used in the short-term to treat symptoms of acute psychosis, or more often in the long-term to prevent relapse and help you stay well. The medicines used in treating psychosis are called ‘antipsychotic medications’.

Antipsychotics work by blocking chemical effects on the brain. One important natural chemical is called dopamine. There are several types of antipsychotics; the main categories are often called “typicals” and “atypicals” (also called 1st and 2nd generation antipsychotics). Research has shown there is no difference in how effective any of these antipsychotics are, but they can differ in terms of the side-effects. One medication called clozapine can be very effective when other antipsychotics have not worked sufficiently well. Clozapine can (rarely) cause serious side-effects and needs careful monitoring.

Other medications may also be recommended, including mood stabilizers (e.g. lithium or sodium valproate), antidepressants such as fluoxetine (Prozac) and benzodiazepines.
(e.g. diazepam or lorazepam) to calm distress or anxiety. Sometimes a medication can be prescribed to deal with specific side effects of antipsychotic medication, for example procyclidine or benzhexol for muscle stiffness and extra-pyramidal side-effects (see below for an explanation).

The length of time that you should take your medication for will depend on a number of factors but long term use is often recommended because it has been shown to prevent further episodes of psychosis.

**Injections**

Sometimes antipsychotic medication is given by injection, when it can be effective for 2-4 weeks at a time. A small test dose is given first and then further injections can be given by a nurse at home, at a clinic or at a GP surgery. Although some people don’t like the idea of injections, this method can be very effective. You don’t need to worry about taking tablets every day and you are less likely to stop medication suddenly, either deliberately or by
accident and evidence shows that this is very important in helping you to stay well. The only atypical antipsychotic medications that are available in this form at the moment are risperidone, paliperidone (which is closely related to risperidone) and aripiprazole. Risperidone long acting injection (RLAI) is given every two weeks, paliperidone and aripiprazole every 4 weeks (after an initial loading dose). Other “typical” injections are often used and some of these can be given every 4 weeks.

**Monitoring**

Side–effects and effectiveness of medications need to be monitored in order to identify or prevent problems. Investigations that are part of routine health check-ups are used, for example an ECG (see below), weight measurement, blood pressure and occasional blood tests are recommended. Most of these tests will be arranged through your GP but you may wish to keep your own record as well (ask your care co-ordinator about this). When you decide to take a medication you will have a chance to regularly discuss how it is
affecting you. You might like to discuss how the medication is working or any side effects. If there are any problems it might be appropriate to make changes to the dose of the medication, the time it is taken or the type of medication.

**Side Effects**

All antipsychotics are equally effective (except clozapine), so the side-effects are an important factor affecting choice of medication. The side-effects vary for different medications. The table overleaf shows a comparison of the more common side-effects of the different (mainly atypical) antipsychotic medications and how likely they are to occur.
**Table comparing the relative likelihood of side-effects of antipsychotic medication**

Note: the side-effects of Paliperidone are the same as for Risperidone.

<table>
<thead>
<tr>
<th>Side-effect</th>
<th>Least likely to occur</th>
<th>Less likely to occur</th>
<th>More likely to occur</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stiffness or involuntary movements</td>
<td>quetiapine aripiprazole</td>
<td>risperidone olanzapine amisulpride</td>
<td>Older (first generation) antipsychotics</td>
</tr>
<tr>
<td>Weight gain</td>
<td>amisulpride aripiprazole</td>
<td>quetiapine risperidone</td>
<td>olanzapine</td>
</tr>
<tr>
<td>Sedation</td>
<td>risperidone amisulpride aripiprazole</td>
<td>quetiapine</td>
<td>olanzapine</td>
</tr>
<tr>
<td>Sexual problems/raised prolactin</td>
<td>quetiapine aripiprazole</td>
<td>olanzapine</td>
<td>risperidone paliperidone amisulpride</td>
</tr>
<tr>
<td>Metabolic Problems</td>
<td>aripiprazole</td>
<td>amisulpride quetiapine risperidone</td>
<td>olanzapine</td>
</tr>
</tbody>
</table>

* But may be a problem, particularly at higher doses
**Stiffness or involuntary movements (extra-pyramidal side-effects):**

These include: akathisia (inner sense of restlessness and compulsion to move), tremor, muscle spasms, stiffness or tardive dyskinesia (abnormal movements - difficult to treat but fortunately rarer nowadays).

**Weight gain:**

This occurs to some degree with all antipsychotics and affects some more than others. Underweight people may return to their normal weight after being unwell. The average weight gain over 12 months for those on quetiapine and risperidone is about 2kg. With olanzapine particularly it may be considerably more. Advice and support with healthy eating may prevent significant weight gain.
**Sedation:**
This can obviously interfere with energy levels and motivation. The impact can be reduced by taking medication later in the day, when it may help to improve sleep.

**Sexual problems:**
These might include loss of sex-drive, reduced arousal and sometimes problems with erections or ejaculation (in men).

**Raised Prolactin:**
Prolactin is a hormone that is involved in the regulation of the menstrual cycle and breast milk production. Raised levels do not usually cause symptoms but can result in breast enlargement (in men and women), milk production (galactorrhoea) and fewer (or stopped) periods (amenorrhoea). It can also cause sexual problems as above. Prolactin can be monitored by a blood test.
**Metabolic Problems (Metabolic Syndrome):**

Some medications can lead to raised cholesterol and lipids (fats) in the bloodstream. The body’s ability to regulate blood sugar levels can be affected but fortunately diabetes is a rarer complication. Blood tests can detect these problems early and if a healthy diet and exercise are not enough, treatment or a change of medication may be required.

**Other Side-effects:**

Low blood pressure (hypotension) can occur, and sometimes the pulse rate increases (e.g. with Quetiapine) but this is not dangerous if monitored closely. ECG (heart trace) changes can occur rarely. An ECG is recommended if there is a history of heart problems, if you need to be in hospital or if higher doses are required.
# Physical Health, Side Effects and support

<table>
<thead>
<tr>
<th><strong>What we can do</strong></th>
<th><strong>What you can do</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Arrange a medical review.</td>
<td>• Arrange a physical health check with your GP/blood tests.</td>
</tr>
<tr>
<td>• Complete a Physical Health Checklist.</td>
<td>• Let us know if you are having any problems with your medication.</td>
</tr>
<tr>
<td>• Your Care Co-ordinator can help you to monitor any side effects.</td>
<td>• Eat a healthy diet.</td>
</tr>
<tr>
<td>• Help you to develop a health record.</td>
<td>• Exercise regularly (for example come to our groups like football and badminton).</td>
</tr>
<tr>
<td>• Support you around your medication.</td>
<td>• Consider making other lifestyle changes (e.g. giving up smoking)</td>
</tr>
<tr>
<td>• Support you around your diet and nutrition</td>
<td>• Keep your GP up to date with your progress.</td>
</tr>
<tr>
<td>• Keep your GP up to date with your progress</td>
<td>• Monitor your weight and other measurements.</td>
</tr>
<tr>
<td>• Monitor your weight, Body Mass Index (BMI) and/or waist circumference</td>
<td></td>
</tr>
</tbody>
</table>
Finding the right medication for me

How important do you think the following side effects are?
   Give yourself a rating out of ten for each.

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Rating</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stiffness or Involuntary Movements</td>
<td></td>
<td>1 2 3 4 5 6</td>
<td>7 8 9 10</td>
</tr>
<tr>
<td>Weight gain</td>
<td></td>
<td>1 2 3 4 5 6</td>
<td>7 8 9 10</td>
</tr>
<tr>
<td>Sedation</td>
<td></td>
<td>1 2 3 4 5 6</td>
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<td></td>
<td>1 2 3 4 5 6</td>
<td>7 8 9 10</td>
</tr>
<tr>
<td>Metabolic problems</td>
<td></td>
<td>1 2 3 4 5 6</td>
<td>7 8 9 10</td>
</tr>
</tbody>
</table>
Frequently Asked Questions

For how long will I need to take medication?

It depends on whether you have experienced only a single episode or more than one. There is very good evidence that medication should be continued for 2 years after a first episode in order to prevent relapse and longer after further episodes. It is important to look at the benefits and difficulties for each person in order to get the best possible recovery.

What will happen if I don't take it?

If you miss an occasional dose it is unlikely to cause any problems. You may notice some difficulty sleeping or feel a little more alert and possibly more anxious. If you miss a dose by accident, it is better to take your normal dose the next day rather than take more to catch up. If you stop taking medication completely, you may feel ok or even better at first but there is often a delay of several months or more before the effects show themselves. You may
relapse or develop similar symptoms to those previously experienced. It is (almost) always better to come off medication gradually.

**Are there any other treatment choices if I decide not to take medication?**

There are some treatment options other than medication but these are not generally effective when used on their own except possibly in mild cases. Aspire and other early intervention teams use many of these treatments alongside medication. These can include psychological therapies including cognitive behavioural therapy (CBT), family interventions, supporting physical well-being, omega-3 fish oils, promoting social recovery, identifying early warning signs and helping you to achieve meaningful goals in many other ways. The role of medication is important, so the aim is to use as little as possible.
What advice and support can I expect should I decide to come off medication?

We will aim to support you whatever your decision.
When someone is very unwell or at risk, they can sometimes be forced to accept medication (under the Mental Health Act), but we believe that wherever possible people should make their own informed choices about their treatment. Some of the websites offer advice and information and there may also be a group running locally that focuses on thinking about medication.

Getting the most out of your doctor and care co-ordinator

Talking to professionals can be hard in consultations due to time restrictions and it can be difficult to communicate your concerns or ask questions. Preparing questions in advance will allow you to gain the most from your meetings. It can also help to make you more
involved in decisions about your treatment. Hopefully this information will have answered some of your questions but if you wish for clarification the following websites may be helpful.

**Useful Links**

http://www.choiceandmedication.org.leedsandyorkpft
http://www.aspireleeds.com
http://www.rcpsych.ac.uk/usefulresources.aspx
http://www.mind.org.uk
http://www.rethink.org/living_with_mental_illness/treatment_and_therapy/medication/
Tips for getting the most from appointments

*Prior to your appointment*
- Note the questions that you want answered
- Write down the details of symptoms, for example when they started, what helps and what doesn’t
- Organise for a friend or family member to come with you if you feel this would help.

*During your appointment*
- Do not be afraid to ask for clarification if you don’t understand
- Write down the important points you have discussed with the health professional

*Before you leave your appointment*
- Check you have covered the questions you brought with you.
- Make sure you understand what you have discussed.
- Know what should happen next.
- Ask who you can contact if you have any questions or problems
- Ask if there are any support groups and where you can obtain reliable information.
Physical Health
In aspire we recognise that good physical health can have a positive impact on emotional wellbeing. We encourage people to make positive steps towards leading a healthy lifestyle through healthy eating and becoming more physically active.

**What are the benefits of healthy eating and being physically active?**

Benefits to how you feel physically and mentally:
- More energy
- Less stress and anxiety
- More relaxed
- Feeling more comfortable with your body
- Feeling fitter and more agile
- Sleep better
- Doing psychical activities can be fun
- Social benefits of exercise i.e. meeting people
- Increase confidence
- Sense of achievement

Helps to prevent physical illness in the long-term by reducing risk of:
- Coronary heart disease and stroke
- High blood pressure
- Type 2 diabetes
- Some cancers (such as colon cancers)
- Obesity
- Joint and bone problems such as arthritis

Recent research has demonstrated that experiencing mental health problems can have an impact on your risk of developing a range of physical health problems including heart disease and diabetes because of related side effects from medication and lifestyle factors. For this reason it is important for mental health services to provide support around preventing or reducing these risks to avoid premature physical illness and reduce health inequalities.

**What can be done?**

It is recognised that the following are key for good physical health:

**Maintain a healthy body weight:**
- By having a healthy diet.
- Keeping active.

**Reducing unhealthy habits**
- By stopping or reducing smoking.
• No excessive use of drugs and alcohol
• Reduce times when not active at all such as, watching TV, playing video games or using a computer.

**How can we help?**

• We will complete a physical health checklist with you to review your current needs and identify any support you need around physical health.
• We can agree an action plan around physical health, with personal, achievable goals.
• We can monitor your weight and waist circumference.
• We have a number of social activities for aspire clients (Badminton, Tennis, Football, Walking group) that promote physical activity; they are good for your recovery and for your health.
• We have a member of the team who can offer nutritional advice.
• We have members of the team who are trained in drug and alcohol misuse.
• Support you to look after your physical health alongside your mental health and review this on a regular basis.
• We can support you to access your GP or liaise with them about physical health needs.
• We can help you access community physical health resources.

**Sexual Health**

At aspire we can support you with any issues related to sexual health. These can include feeling comfortable with your sexuality and in sexual relationships, practicing safe sex, using contraception or family planning advice, being clear about consenting to have sex and how to manage situations when you feel vulnerable. We can provide you with support and advice and signposting to specialist services where required.

We hope we can help you feel able to share any questions or concerns you may have about this topic, we recognise that people have different views, experiences and beliefs about sex and we will respect your wishes when discussing your support needs.

For clients who wish to receive specific support and advice around lesbian, gay, bisexual, trans* and queer (LGBTQ) needs we do have a specialist worker who you can arrange to see.
Service User involvement
How to get involved

Action Afternoon

Have your say in what activities and projects you’d like to do with aspire, in our weekly Action Afternoon meetings.

If you would like to be involved in developing a program of activities, projects, one day workshops and short courses to empower, improve your skills, meet new people and promote recovery and well-being then you might like to join Action Afternoon.

We meet every week for 2 hours. If you are interested in joining you can ask your aspire worker for more information or alternatively you could contact our Support, Time and Recovery worker on 0113 2009170.

Website, Facebook and Twitter

We use our website as a dynamic source of information about aspire and psychosis and all the topics that are covered in this information pack. The website and our Facebook page includes information of what activities we run and gives you the opportunity to get involved, either by providing feedback or linking in with people or groups from aspire.
As a person using aspire, you could become a member of Action Afternoon. Action Afternoon members get involved with updating the website and its content. Some people are given specific tasks or take a lead on specific sections. Occasionally we run focus groups, which look at reviewing and updating the information on our website and face book page, as your views and opinions can help ensure they stay useful and relevant.

Find us on Facebook
www.facebook.com/aspireCL

aspire encourages the use of Community Links website twitter and Facebook accounts to get involved with the larger organisation. To find out more go onto the organisations website.

www.commlinks.co.uk

If you are not familiar with using social media then please speak to your aspire worker about the best way to support you with learning how to do this.

**Consultation events**

At aspire we run consultation events for aspire users and their family and friends. These events are designed to:
• Give you a chance to have your say in what aspire does and how we deliver our service.
• Discuss ideas for our service plans.
• Update you on relevant service feedback and evaluation.
• Answer your questions about the service.

This will help us to:
• Improve the service we provide to young people and families
• Show we are evaluating and reviewing our service
• Be valued by our NHS commissioner and help us seek future funding for aspire
• Show that we listen and are responsive to the views and opinions of all our stakeholders

We hope our consultation events will not only be fun and informal, but informative and beneficial for you. We arrange events at different times and locations to fit in with the different lifestyles of the people using our service and their family and friends.
Getting involved with Community Links

Community Links as a wider organisation believe that we can provide better services by involving the people who use those services in the planning, monitoring and evaluation of them.

Effective participation happens when those involved are satisfied with the level of participation at which they are involved and have a meaningful role in the development, monitoring and evaluation of the services.

See how you can get involved by looking on the community links website:

www.commlinks.co.uk

Service user feedback questionnaires

All of our service users are asked to give us feedback on the service they receive. This is one of the most effective ways of getting involved and having an impact on how the aspire service is provided by telling us about your experience of the service. Each year every client will receive an ‘annual service user satisfaction questionnaire’ and once you are approaching discharge from the aspire service you will be given an exit questionnaire. Each questionnaire aims to be as short as possible, but give you a valuable opportunity to give
honest feedback about the support you have received. By taking time to complete and return these you are:

- helping the aspire service to check that we are helping meet the needs of those who use our service
- identify ways we can improve
- Help secure continued NHS funding to continue to deliver support.

If you would like to give us feedback at any other time, you can send us a postcard with your comments, views and ideas about aspire. We have included a blank postcard at the back of this pack, or more are available in the aspire office or can be downloaded from the website.

**Research**

Another way to get involved in helping the service is to consider taking part in some of the research projects that aspire participates in. In order to find out what aspects of care and treatment are most helpful and effective, we at aspire, sometimes support research studies that involve service-users. Many people are keen to participate in studies (depending on what they are), whilst others are less sure or else do not wish to be involved under any
circumstances. Often there may be a small payment to compensate for people giving up their time.

If you are interested in taking part in a research study for which you are eligible, we will gladly let you know of any that come up, you then can decide whether or not you want to take part. Please either fill in the research form at the end of this booklet, or speak to your aspire worker.
Your rights and what we expect from you
Statement of respect

aspire is an inclusive and positive Community Links service working with over 300 young people and a large staff team. As a large community it is important for everybody to feel that their rights are being considered, we request that all who are part of the service, young people, families and staff alike, abide by the following Statement of Respect:

*We respect the right of all individuals to hold their own beliefs and live in the way that they choose (whilst being mindful of the feelings and safety of themselves and others.)*

*We encourage the inclusion of young people from all backgrounds to engage with the service in both individual and group settings to increase mental wellbeing and promote recovery.*

*We want everyone involved in the aspire service to feel comfortable, safe and respected.*

Below is an outline of what you can expect:

- To feel safe
- To feel supported
- To feel welcome
• To be listened to
• To be able to get involved at the level you feel comfortable with
• To be included
• Other people to behave appropriately towards you, respecting your views, preferences and beliefs
• Staff to be good role models and manage any difficult situations.

We will expect you to:

• Treat others with respect
• Take personal responsibility for your own behaviour
• Ensure you are not drunk or under the influence of drugs whilst engaging with the service
• Not use threatening or intimidating behaviour
• Respect the right of others to have different views, preferences and beliefs
• Let a member of staff know if you feel you are not treated in accordance with this statement

Where staff, clients or family members do not abide by this Statement of Respect, aspire will address the issues in accordance with the appropriate policies and procedures of Community Links.
**What is Confidentiality?**

Confidentiality is a key principle that all health care professionals must adhere to. It applies to personal data including name address and date of birth, and information about support and treatment and any other information you share with aspire. This information will be kept safe within the service and unavailable to individuals you do not want to share this information with. We always aim to have an agreement with our clients about what information and who we can share this information with and may encourage you to consider the benefits of sharing more information with those who are close to you.

We will ask for permission to use or share the information you provide to us. Only in exceptional circumstances will we use your information without gaining your consent. This might be in the case of an emergency, if we were worried about your own, or somebody else’s safety or if we were required to by a court order or an act of law.
**aspire’s Statement to consent:**

In working with aspire, our service will assume that clients are giving their consent to support and or treatment. If you are under the age of 16 then consent may be agreed with parent or guardian.

Treatment can include medication, visits from members of the aspire team or different therapies. The client’s named aspire worker will discuss with them the support/treatment options thought to be the most helpful. In giving their consent to treatment, aspire clients also have the right to review or stop this treatment at any time. Clients are encouraged to raise any concerns or questions they may have about their support and treatment with their worker or any other relevant member of the aspire team. If clients do not wish to receive a particular type of support/treatment then we encourage them to inform their aspire worker and we can review the care plan. We also aim to offer information to appropriate family and friends/partners about support and treatment. It is important that we work collaboratively and that clients feel they are being heard and respected.

The occasions we may not be able to take consent into full account would be when there are serious risks or significant concerns that a client’s judgement is impaired by their mental state. This may include assessment under the Mental Health Act (1983). Please speak to your aspire worker for further clarification of these issues.
**Breach of confidentiality or right to consent and complaints procedure:**

If you feel that your confidentiality or your right to consent has been breached then you should ask your aspire worker to give you a copy of the Community Links Complaints policy. If you still feel that your confidentiality has been breached then you have the right to make a complaint. There is a specific leaflet you can request to do so, or visit the website: [http://www.commlinks.co.uk/comments-compliments-complaints](http://www.commlinks.co.uk/comments-compliments-complaints)

**Mental Health Advocacy**

All individuals receiving treatment within the community or hospital have the right to receive support from a mental health advocate. The role of a mental health advocate is to inform the individual of their rights in relation to the treatment they are receiving, how to use their rights and answer any questions they may have. Please contact:

**Advocacy for Mental Health and Dementia (A4MHD)**
Micklethwaite House
70 Cross Green Lane
Leeds
LS9 0DG

Telephone – 0113 236 5900
Website - www.a4mhd.org.uk
Email - office@a4mhd.org.uk
**Information Sharing**

Your information - How we use it and how we keep it safe

**Why we keep information about you**

It is essential that we are able to see accurate information about you to make sure that the support we provide you is safe and effective. While we keep some paper records these are not always quickly accessible or in the right format to quickly share information with other mental health services when we need to. Electronic records can be seen by the right people whenever they are needed. As well as helping us record your information effectively it can be helpful when you may need support from other mental health services, particularly at nights and weekends. They would be able to access the information they would need to effectively support you outside of aspire’s working hours.

**Patient Record Information Systems**

aspire is now using PARIS (Patient Record Information Systems). This is an electronic system for all service users 18 years and over who are registered with a GP in Leeds.
What are the benefits for me?

Security

Modern computer systems are protected by strict security procedures. Records are held securely and information is only accessed by those who need to see it — those people directly involved in your support.

Quality

We will take appropriate steps to make sure that information about you is correct. To do this we will ask whether what we have recorded about you is correct (address, contact number, next of kin etc).

Keeping It Accurate

We regularly check and update the information that we keep about you to ensure it remains accurate and up to date. You can help us with this by letting us know about any changes to any of your details.
Tracking

The PARIS system keeps a log of everybody who accesses your records and when they do so. You can ask us to ensure this access is appropriate.

Are there any drawbacks?

aspire, as part of Community Links, has policies and procedures in place to ensure information is held securely and used appropriately. You have the right to confidentiality under the Data Protection Act 1998, the Human Rights act 1998 and the Common Law Duty of Confidence. Community Links has a legal obligation to ensure that all of its systems are managed in compliance with the above legislation.

Keeping It Confidential

Everybody working for aspire has a duty to keep information about you confidential and secure.

Further Information

If you would like to know more about how we record and use your information then you can speak to your aspire worker who would be able to answer any questions you might have.
Service contact information
Website

www.comlinks.co.uk/sites/aspire

How to contact us

At aspire our office working hours are 9am till 6pm Monday to Friday and we can usually be contacted on our office numbers during this time. We also provide some direct client support on Saturdays but are unable to respond to referrals at the weekend. You can contact us on the main number below.

Main Number: 0113 200 9170
Fax Number: 0113 249 3411

Individual workers will often be out and about working around the city, so please leave a message at the office during these times. If individual workers are in meetings etc. they may not be able to respond immediately, but will get back to you as soon as possible. If you feel you need to speak to an individual urgently, please contact us on the main office number.
**How to find us**

Our address is Suite 5, Bank House, 150 Roundhay Road, Leeds LS8 5LJ.

**Out of hours**

If you feel that you are in a crisis situation outside our office hours you can contact other services for immediate support at these times.

**Crisis contacts**

Your own GP and their out of hours contact numbers.

111 NHS telephone emergency and urgent care services

Connect Helpline (Leeds Survivor Led Crisis Service)
0808 800 1212 www.lslcs.org.uk

You may be able to access the NHS crisis team if this is part of your care plan. Please refer to your care plan document for more specific information for yourself or liaise with your aspire worker.
Additional Forms
RESEARCH FORM

Please can you indicate your preference below by crossing out the statement(s) that DO NOT APPLY and giving this page to any member of the team. That way we know who is interested and who would prefer not to be approached.

A) Yes, I would like to be informed of any research studies for which I may be eligible. I understand that this does not commit me in any way to taking part.
B) No, I would prefer not to be informed about any research studies, although I retain the right to change my mind at any time.
C) I would be interested in joining a group where service-users can discuss what research would be helpful to themselves and others.

NAME____________________________________________________

Some of the studies that are underway at the moment include:
A survey of substance use including “club drugs”
Developing a service-user held physical health record
A study looking at genetics and symptoms in psychosis (£15)
The Bipolar Disorder Research Network study (Stephen Fry took part in this)
OCTUMI-4 trial of Mirtazapine/Folic Acid (a vitamin) or placebo in psychosis

Coming soon – A trial of a lifestyle intervention to reduce weight for those on medication

Please ask for further information if you are interested in any of these, or contact the office on: 0113 2009170.