

The
HUDDERSFIELD SUPPORT GROUP FOR AUTISM

REGISTERED CHARITY NO: 1061957



SUPPORT PACK

(Or, don't worry, you are not alone)

There could be more than 600,000 people in Britain with an Autistic Spectrum Disorder. This pack was originally written to help parents and carers in Huddersfield at a difficult time. Since then, the National Autistic Society have produced a very Professional one. So, we've done 'Our bit' - This gives you local information and contact details.

The Huddersfield Support Group for Autism is affiliated to the National Autistic Society



We hope it helps.....

HUDDERSFIELD SUPPORT GROUP FOR AUTISM

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INTRODUCTION - The history and aims of HSGA

This pack has been produced by parents of the Huddersfield Support Group for Autism. We intend it to be a resource for the parents of children with Autistic Spectrum Disorders (Autism, Asperger's Syndrome, High Functioning Autism etc.) who have recently received a diagnosis.

The Huddersfield Support Group for Autism (HSGA) was set up in 1992 by a very committed Senior Speech and Language Therapist and a small group of parents. Since then the group has grown in size and now has a membership of over 300 families and professionals in the Huddersfield area.

The number of members has grown rapidly because of the increased awareness of autism and recognition of the need for help. Happily though, this is good news - the earlier autism is diagnosed and understood, the better. With suitable 'handling' the outlook does improve.

Our hope is that the pack contains materials and contact names which can help people through what we remember to be a very difficult time. Unfortunately it is very difficult for us - parents like you just a little further down the road - to keep this information accurate and bang up to date so, sorry, we can't accept responsibility for any problems that might occur because of this!

We hope that you will find the enclosed information and advice to be useful and that, if you wish to, you will feel able to ring one of the parents who have agreed to be available to talk to on the 'phone.

For many of us the opportunity to talk confidentially and privately with another parent who had been through the same experience was a great help, especially in the period following diagnosis. Appendix 1 lists some contact numbers.

Broadly, we aim to provide advice and support to families and carers of people with autism, to increase public awareness of the condition, foster mutual help between families, carers, helpers and professionals and promote the provision of care, treatment and education of children and adults with autism.

We also aim to make appropriate representations to relevant bodies and organisations on behalf of people with autism and their families and carers.

HSGA - What do we do

Direct activities to support people with autism

- A Saturday afternoon swimming club for children with a qualified swimming teacher in a private pool session at Huddersfield's Galpharm Stadium. The session lasts one hour starting at 4.00 pm.
- The HSGA Summer Playscheme provides up to 80 children with two or three weeks of high quality play activities - from swimming, bowling and farm visits to T-shirt making. The playscheme costs a lot to run and is dependent on grants and fundraising.

- Trips to the Seaside, play-gyms, Magna and Chester Zoo. Since 1997 we have run various very popular annual coach trips.
 - We have worked with Shebang Theatre Group offering the families and children the opportunity to experience wonderful creativity with music, vibrant colours and dance.
- Support for parents and carers of persons with autism.**
- We hold bi-monthly monthly support group meetings on the third Friday of the month at the Ellerslie Centre, rear of the Princess Royal Health Centre in Greenhead, Huddersfield. We meet from 7pm to start at 7.30pm with informal chat, advice sessions from fellow carers and professional guest speakers.
 - We have been able to inform about benefits, service provision and provide a general telephone/personal network of contacts - either for advice or just someone to talk to who understands. These meetings have become rather poorly attended so we now alternate the meetings with social events and quizzes. All our events are open to everyone, including children. See our website for details of dates for meetings etc.
 - Access to the support group library (see below) enables parents/carers to keep up to date with developments in autism. We have an extensive collection of books, periodicals and pamphlets. The library is run by a group member.
 - Work with service providers to promote services for people with autism. During the early years we were instrumental in securing additional specialised educational provision in Huddersfield through the LEA. We are represented on a multidisciplinary (Health, Social Care, Education) working party on autism.
 - We have been consulted by service providers on planning for respite care provision, the Kirklees Young Citizens plan, Playscheme provision, Speech and Language Therapy provision, the Parent Partnership, and recently Kirklees Council regarding provision for Adults with ASD.
 - We funded training for a Speech and Language Therapist to attend a course on the 'Hanan method' so that she could then train parents to work with their own children. We also provided a subsidy for some professionals to take up the Autism Distance Learning Course based in Birmingham University.
 - The HSGA support pack provides a resource for parents / carers on diagnosis to enable them to make contact with people who 'have been there before them', lists possible sources of help and provides a picture of services for people with autism. This is based on the National Autistic Society's pack with additional local information about schools and local support contacts.
 - The monthly HSGA newsletter aims to give parents/carers a chance to contribute and pass on advice to others; keep members up to date with events and other work the group may be doing; provide an interface between parent and professionals; link parents with the activities of national groups like Mencap or the National Autistic Society.

Information and Education

- In the past we have run annual Study Days. However, the National Autistic Society now organises the 'Help!' programmes which are a series of local workshops on a range of topics. These are usually free and well worth attending. We notify you of them in the newsletters.
- Through the HSGA newsletter we seek to inform both parents and others. Nearly 300 newsletters are sent out each month, approx. 80% of these to parents and carers - the rest to a mixture of professionals in Health, Social Care and Education.
- We aim to be active during Autism awareness week by contacting the general public to hand out leaflets and raise the profile of autism locally. We intend to mount a similar campaign each year.
- We have been successful in securing coverage and feature articles in local newspapers radio and television where members of the group described their experiences and gave general information about autism.
- The library is available for use, on a free basis for members of the general public and professionals. It is 'advertised' through visits to schools and through the newsletter.
- Support group members have been asked to provide training on autism for local schools, respite care providers and adult carers.
- Lobbying and Policy making - HSGA is actively involved with local service providers, Health, Education and Social Services - we aim to advise and represent parent's views when policy decisions are made.

Research - HSGA has been involved with research programmes on diet and autism.

LIBRARY

To try and help, HSGA has set up a library which is open to you. We have over 300 books, periodicals, leaflets, videos and articles on autism. These are available for free loan to members and local professionals.

The books are currently kept at the Eilerslie Centre and to borrow one all you have to do is fill in the details in the record book.

The library is organised by Sheena Fitzsimmons. (see Appendix 1). If you have any specific books that you would like to read and can't get, please let Sheena or the committee know. If you would like suggestions on books about a specific subject, we'll help there too.

There have been several TV programs about Autism. Be careful what you watch, some of them are very sensational and can be depressing. The good bits about Autism don't make good television!

Some of these videos are available from the Library. We also have videos of previous study days.

Probably the best way to understand more about autism is to read books written by people who have autism themselves e.g. Luke Jackson, Donna Williams, Temple Grandin, Wendy Lawson, Jasmine O'Neill, Clare Sainsbury and Liane Holliday Willey - to name but a few!

In earlier times (many books written before the eighties), 'experts' blamed autism on poor parenting. This is NOT a view held seriously now, autism has genetic and biological causes. Reading such books can, obviously, depress you further when there is no need. There are many hundreds of very valid texts and scientific papers on Autism and associated disabilities. DO NOT TRY TO READ THEM ALL! You will go mad.

FUNDRAISING

Our services and activities cost money! We subsidise our trips and social events very heavily so that as many families can take part as possible. The group is financially strong but is heavily dependent on regular fundraising events. We have received grants from bodies such as the Children in Need, National Lottery, Kirklees Council, West Yorkshire Health Authority, The Huddersfield Trust Clinical Support Services and the Common Good Trust. These have to be applied for every year and we are always grateful for help and advice from people who are good at filling in forms!

We conduct our own fundraising events and activities:

Quiz Nights. We have regular quiz nights at the Victoria Hotel, Newsome. These are great fun and you can bring your children along.

Concert Nights. We have put on some excellent concert nights. We have some very talented parents who perform brilliantly to help the group. The Abba Tribute Concert was brilliant. Contact Mick Orwin if you can provide raffle prizes or performers!

Charity Nights and sponsored events. Harriet Ward recently ran a very successful Curry Night on behalf of the Playscheme, Kim Watson organized bag packing at Morrisons... we are eternally grateful to all families and friends who organise events on our behalf.

We have received some wonderful donations and it is thanks to such generosity that we can continue to subsidise all our activities. Many individuals have contributed through running marathons and the like.

We are always delighted if people take part in the Examiner Walk and Ride on our behalf. If you possibly can, please support our fund-raisers. We would love to see more families at these events and you can bring your children along.

Of course, you don't have to join HSGA. We ask members to consider paying just £5 per year (this covers production and mailing costs for the newsletter) but this fee is not compulsory. Some members are very active; others just receive the newsletter. However, we are here if you want us and you will be made very welcome.

INTRODUCTION

The diagnosis of autism is a complicated issue. The current waiting time to see the Diagnostic Team is 6-8 months, although this may increase as there have been some funding cuts. After assessment the team produces a report which is usually sent out within a month of the feedback appointment.

North and South Kirklees have one shared waiting list but two teams (Kirklees Multi-Agency Autistic Spectrum Disorder Assessment Teams). They run two clinics (Dewsbury is in Dewsbury Health Centre and Huddersfield is at The Ellerslie Centre or Glen Acre House).

There is a separate ASD assessment team in Calderdale that runs slightly differently. Currently (Jan 2011) the members of the **Huddersfield** Team are:

- Dr Katie Moizer, Clinical Psychologist
- Dr Kay Harvey, Consultant Psychiatrist
- Penny Sheard, Educational Psychologist
- Sarah Fox, Speech and Language Therapist (school age children)
- Anne Griffiths/Julie Brian, Speech and Language Therapist (pre-school children)

The team in **Dewsbury** consists of:

- Dr Shirley Gordon, Clinical Psychologist
- Dr Katie Moizer, Clinical Psychologist
- Christine Clark, Educational Psychologist
- Debbie Hinchcliffe, Play Development Lead
- Jackie White, Speech and Language Therapist.

The medical care for people with autism in Huddersfield is largely through this team, the Ellerslie Centre and the family GP. This care consists of:

- Ellerslie- a specialist nursery in the Princes Royal Community Health Centre in Huddersfield. Children with communication difficulties are seen individually or in structured group sessions, depending on demand.
- Speech therapy - Speech and language therapy/advice will be provided as appropriate. Ask your Paediatrician, Health Visitor or GP about referral.

Advances in research suggest that the case for there being ongoing biological contributors to the behaviour displayed by people with autism is growing stronger all the time. The established treatment for autism is through educational means but there is limited medical help or intervention. The local health professionals are very open minded with regard to the latest research and discussions as to the validity of that research is ongoing between the HSGA and the local professionals.

NUTRITION

Please note that the HSGA does NOT endorse any specific dietary or alternative treatments for autism but will try to offer advice.

As mentioned above not inconsiderable research is going on into several areas of research with regard to Autism. Many of these relate to nutrition and autism.

HSGA as a group has shown considerable interest in this area and some parents have felt that dietary factors do influence their child's 'autism'. Intolerance to gluten and/or dairy products seems to be significant for some children.

Many of the children have been tested for vitamin and other deficiencies and some are on specialist diets.

If you would like to know more about this then phone Will Penman or consult the HSGA library.

ALTERNATIVE THERAPIES

There are many proposed therapies for autism. Some of them are more 'way out' than others and some are extremely expensive.

HSGA would suggest that you talk through these prior to instituting any therapy regimes in your family. The person to talk to is Kate Falkingham (see Appendix 1).

Some of the therapies that you may come across are: ABA/Lovaas, Sensory Integration, Options (Son-Rise), Music therapy, Non-Directive therapy. Again there are books and articles available in our library.

Many of our members will have direct experience of one or more of these therapies - it can be useful to talk!

EDUCATION

Education is possibly the only 'treatment' for autism which has actually been *proven*, to really help.

Educational provision for autism is patchy across the country as a whole and in Kirklees we have what is probably an above average service which is improving all the time.

THE KIRKLEES AUTISM OUTREACH SERVICE (KAOS)

Who are they . . . ? The Kirklees Autism Outreach Service (known as KAOS) is a very important part of Kirklees' services towards autism. The team currently consists of an Educational Psychologist, Chris Clark, as Team Leader, two Outreach Teachers, Esther Marper and Peter Miller and three support workers, Gillian Hinchliffe, Karen McKeivitt and Julie Hargreaves. Their primary role is to provide specialist support and advice to school staff and to parents.

Aims. . . Their aim is to promote knowledge and understanding of the difficulties experienced by children and young people with an autistic spectrum disorder.

Their level of support to school and to parents is offered on a flexible basis depending on the nature of the difficulties. They support staff with drawing up autism specific targets and will recommend the most appropriate interventions to achieve those targets. They work within an inclusive practice and this support is proving to be invaluable as it is helping the majority of children with autistic spectrum disorders to thrive in the mainstream environment.

Family Support Worker. . . .The Kirklees Autism Outreach Service currently has a half time post to offer support and advice to families who have recently had a diagnosis of an autistic spectrum disorder. This is a limited role but the aim is to help parents through the initial stages following diagnosis and signpost them to all the support and agencies that are out there. In addition, team members aim to offer further advice to parents experiencing difficulties with their child at any age. They try to work closely with parents and school staff to bring about the best outcome, both at home and in school.

PORTAGE

Portage is an outreach service that is run to help support pre-school age children. It is a teaching service designed to enable parents to educate or teach their own children different skills or tasks in their own home, through the help and guidance of a Portage Home Visitor and an educational psychologist.

THE BUTTERFLY PROJECT

The Butterfly Project is a behaviour management based programme that is based on clear simple instructions and positive social interactions. It is aimed at supporting children from the ages of three years old to seven years old in school and at home. It aims to work with parents and teachers, who have children who are displaying emotional, social or behavioural problems.

An educational psychologist, a mental health worker and a family advisor will work alongside the parents and teachers, on the use of positive reinforcement and the use of simple clear instructions.

Contact them . . .If you would like to know more, the team would be delighted to hear from you. Please contact them.

The psychology and specialist outreach team, are based at the Child and Family Consultation Centre, Temple Road, Dewsbury, WS13 3QD.

The Kirklees Autism Outreach Service team can be contacted on the following telephone number: 01924 324850 or email dewsbury.psychology@kirklees.gov.uk.

Referrals to KAOS can be made by parents or carers, school staff and other professionals.

In special needs education there is a lot of jargon. Please see the glossary if you are unfamiliar with any terms in this document.

STATUTORY ASSESSMENT

If you have this support pack, then someone has already determined that you have a child who is, or may be, on the autistic spectrum. This may also mean that your child will have special educational needs. The first thing which must happen is that the LEA is asked to make a Statutory Assessment. This sometimes called 'statementing'.

If your child is already at school then it may be that the school has already started up the process. You do not have to rely on the school to contact the LEA and you do not have to wait until your child is due to start school.

The earlier this process starts - the better. Early diagnosis is often crucial in helping support children, and thus helping them to progress. Parents or the Health Authority can also refer your child to the LEA for assessment.

What is it . . . ? This is the process by which the child is formally assessed by the LEA to determine their Special Educational Needs and what additional help your child may need. If necessary, the LEA then writes a proposed *Statement of Special Educational Needs* which sets out the child's needs and how they are to be met (additional resources, type of school, support assistants etc.). On diagnosis, discuss referral for Statutory Assessment with the health professionals or your child's school.

How long does it take . . . What you need to write depends upon the age of your child and whether they are already at school or not. For a pre-school child (up to nursery age - 3½) explain that your child has just received a diagnosis of autism and request that the LEA starts up the statutory assessment process. The process should take no longer than six months, though there are circumstances where this period is extended. Once started, the Statutory Assessment timetable should look something like this:

Weeks 1-6 The LEA considers whether a statutory assessment is necessary, with a yes or no outcome.

Weeks 7-16 (If continuing) The LEA makes the assessment.

Weeks 16 Parents are informed of the decision to make a statement of SEN or not.

Weeks 16-18 The LEA writes the proposed statement, in a draft form.

Weeks 19-20 Parents consider the statement and respond to the LEA

Weeks 21-26 The LEA writes the final statement.

Appeal . . . There are, of course, opportunities to appeal against the decision of the LEA. If you disagree with any part of the proposed statement of your child's special education needs, then you should discuss it with an officer of the Local Authority.

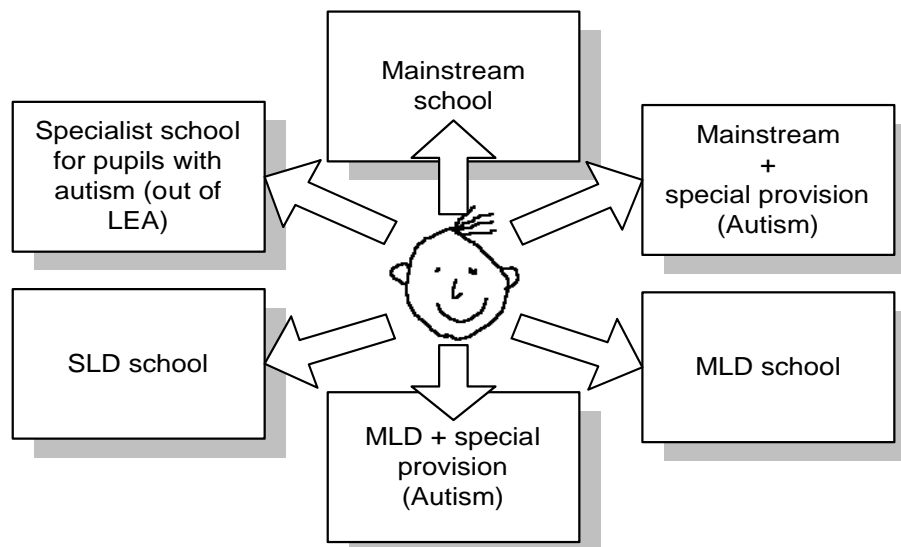
Contact . . . For more information on any of the above please contact the SEN Administration Service, you can contact Kate Mawer in writing or in person at The Special Educational Needs Administration Service, Pupil Support, Civic Centre 1, Huddersfield, HD1 2NF, tel 01484 225057. For more information on any part of the statutory assessment please ASK!

LOCAL SCHOOL PROVISION

Remember that children with autism have a very wide range of different needs. A high proportion of children with autism also have additional learning difficulties. Some are of average or above average 'intelligence' but still have great needs. Therefore it is not possible to recommend one single type of school for every child. In Kirklees the following types of school are available *and any of them may be appropriate*.

In some cases it *may* be appropriate to request that the child is educated in a specialist *school* for children with autism. This is unlikely to be the best provision for the majority of children with autism. In certain cases the specialist school may be outside of the Kirklees area. Listed below are the different types of school that are available, with some suggestions of an actual school in the area.

- Mainstream school - Primary/Secondary
- Mainstream school + resourced provision for autism / communication difficulties:
Huddersfield - Honley High School (for 11 to 16 year olds), Moldgreen Community Primary School School (for nursery to 11 year olds)
Dewsbury - Headlands Junior, Infant and Nursery School (for nursery to 11 year olds)
- MLD (Moderate Learning Difficulties) Schools - Lydgate School, Ravenshall School
- MLD + resourced provision for autism - Longley School
- SLD (Severe Learning Difficulties) Schools - Castle Hill School, Fairfield School
- Out of authority specialist schools. (There will inevitably be some children whose needs are so complex that the LEA will not be able to provide a suitable placement, and hence a school outside of the local authority will be suggested) - Holly Bank School or Robert Ogden NAS School.



We all need help with this. Please ASK! Many people in the support group have experience of this process. It will be worthwhile to speak to as many people as possible about the process. (For contacts see Appendix 1).

BENEFITS

INTRODUCTION

There are many important benefits available for disabled people - and most people with an autistic spectrum disorder have a disability and could therefore be eligible for such benefits.

All benefit application forms seem to have been designed to put people off applying for benefits, but please do apply for any benefit that you feel you are entitled to.

It is worth seeking help with completing forms from the numbers and services listed in this section.

This is an area that is riddled with inconsistency. Over and above any benefits that you may be claiming already you should be able to get DLA (Disability Living Allowance).

As to whether you are entitled to any other benefits, this will be down to your individual circumstances. Kirklees benefits advisors can be contacted on the telephone number 01484 416958.

DISABILITY LIVING ALLOWANCE (DLA)

There are two parts to DLA:

1. **The Care Component of DLA.** People often confuse this with the carers benefit (see CA below) and as a result wrongly count themselves out.

The care component is payable to the person who needs looking after, i.e. the autistic child, because they need looking after, not to the carer who does the looking after (see CA below). This means that it does not matter if the carers work full or part time as it is the needs of the child for care, whoever that care comes from, that matters.

There are three rates of the care component low, middle and high and the amounts are £18.95, £47.80 and £71.40 (updated Oct '10).

To qualify for the low rate of care you have to need some help with care.

To qualify for the middle rate of care you have to need quite a lot of help or supervision during the day or night.

To qualify for the high rate of care you have to need quite a lot of help or supervision during the day and night.

When considering the needs of a child up to 16 those care needs or supervision have to be more than a healthy child of the age so this is a harder test to satisfy when considering a very young child.

The youngest age at which you can claim is 3 months in most cases. The oldest age you can claim is 64 (though people over this age can claim another benefit called Attendance Allowance).

2. The Mobility Component of DLA. There are two rates of Mobility component, low and high, respectively £18.95 and £49.85 (Oct '10). There are very great differences in the criteria for the two rates. Generally speaking the higher rate can be claimed by people between 3 and 64 who have physical difficulties with walking such as amputees, people with arthritis and heart or chest problems. If you get the higher rate of Mobility you can also get a blue badge (see below) for parking without difficulty; free car tax; and a parking symbol painted outside your home.

The lower rate is quite different and is very often paid to youngsters with autism even if they can walk very well. If you need guidance or supervision in unfamiliar places you qualify. Youngsters with autism will usually need supervision, even in familiar places, because of their lack of fear of traffic or their lack of awareness of danger. The lower age limit is 5 for this lower rate. There are two other routes to the higher rate of Mobility which may apply to children with autism but the conditions are so difficult to describe that you should ask for advice from someone who is an expert in benefits (ideally before you make a claim). **NO PART OF DLA IS TAXABLE.**

CARERS ALLOWANCE (CA)

This is a benefit that is paid to carers who spend at least 35 hours per week caring for someone who receives, at least, middle rate care component of DLA (or Attendance Allowance). The week runs from Sunday to Saturday so you can often satisfy the 35-hour rule even if the disabled person is in care or hospital for part of the week.

You can do some work whilst claiming Carer's Allowance but you should not earn more than £100 per week. However if you receive certain other social security benefits (such as Maternity Allowance, State Retirement Pension, Incapacity Benefit, Contributory Employment Support Allowance, Widow's Benefit or contributory-based Jobseekers Allowance) then you cannot receive Carer's Allowance.

The basic amount of CA is £30.05 per week but you can sometimes claim extra for dependents (Oct '10). Since October 2002 there is no upper age limit for claiming CA but it is only rarely advantageous to claim if you are 65 or over - Seek advice.

TAX CREDITS

Over the past few years benefits for people who are working have changed a lot. Parents of autistic children may well qualify for extra child tax credit which can be substantially more and is often missed by the Inland Revenue.

You should always check tax credit award letters very carefully and if in doubt, seek advice.

When a child gets to school leaving age there is often a choice between the child remaining a dependent or claiming in his / her own right. This is often a very difficult calculation and if possible parents should seek advice.

WORKING TAX CREDIT

This is an income-related benefit for people who work at least 16 hours a week but have an illness or disability that limits their earning capacity. Claimants must be in receipt of another qualifying disability benefit.

COUNCIL TAX EXEMPTION

Parents of children aged 18 and over should check if they are entitled to be classed as carers by their Local Authority for Council Tax purposes.

BLUE BADGE SCHEME

This is a badge that some persons may be entitled to that gives various parking benefits and concessions and other such privileges.

The disabled persons parking badge scheme, or the blue badge scheme, offers persons the availability to park in disabled parking spaces and sometimes in yellow line areas.

For more information on this please seek advice from the Citizens Advice Bureau.

They can be contacted on the telephone no: 08448487970. Staff are available from Monday to Friday 9.30 till 3.30.

ADVICE

There are many different places where you will be offered advice on the benefits that you are entitled to. If you are in doubt with regards to benefits then please contact one of the places below.

The Benefit Enquiry Line

This is a benefit helpline for people with disabilities and their parents and carers. The Benefit Enquiry Line is a part of the Department for Work and Pensions.

They offer advice and information on various benefits and how you can go about claiming them. Their advisers have no access to customers' personal records and therefore are able to provide general advice only.

The most common benefits that they deal with are those concerning disabilities, such as the above mentioned Disability Living Allowance, or Carer's Allowance and also Income Support.

You can contact them on: **0800 882200**. They can be contacted from Monday to Friday 8.30am - 6.30pm, and on Saturday's from 9am - 1pm.

The Kirklees Benefit Advice Service:

The Kirklees Benefit Advice Service can be contacted to give you advice on any of the above benefits. Please contact them if you are struggling to find specific information on what benefits you might be entitled to, and how you can go about sorting them out. If you live in South Kirklees please telephone: **01484 223950**. For North Kirklees please telephone: **01924 326010**.

INTRODUCTION

There is a wide range of support agencies, designed to help you out in many diverse and different ways. These can seem very uncoordinated - which is one reason why the Huddersfield Support Group for Autism needs to exist! There are many varied and different things out there to offer you help. The best thing to do is attend a support group meeting or ring one of the members listed in Appendix 1, for what may be best suited to you and your child. The newsletter also gives information about other help and advice as it becomes available.

KIRKLEES CHILDREN WITH A DISABILITY UNIT (CWDU)

The Team - its aims . . . The Children With a Disability Unit was set up in 1992 within the Kirklees Social Services Children and Families service area. It was set up in recognition of the needs of children, from the ages of nine months to eighteen years old, who have disabilities.

It was also set up primarily to help support the families of the child too. It aims to provide a dedicated service to help enable disabled children to reach their full potential and to aid their parents and carers with individual support packages drawn from a full range of social work services.

Where they are . . . Social Workers and Community Care Officers are based at Westfields, Westfields Road, Mirfield, WF14 9PW. They can be contacted there in writing or by telephone on 01924 - 326438. Staff are available between 8.45 and 5.15 Monday to Friday for advice and information over the telephone, or to take details if a home visit is requested.

What they do and how they do it . . . A home visit would normally include a full assessment of need, completed following discussion with the child and his or her family and, with the family's permission; the contribution would be sought of other key professionals from Health and Education, for example.

The Social Worker or Community Care Officer will then identify appropriate services, either from another agency or from within the Children With a Disability Unit, which may be able to assist the child and family with difficulties that they may be experiencing.

Occupational Therapy . . . Where the child has difficulty in accessing essential facilities within the home, a referral would be made to the Occupational Therapist for advice on ways of solving that difficulty, which could involve adapting the family's home. These adaptations are designed to help improve the child's home environment and could include such things as a downstairs bathroom, an access ramp or special fittings to ensure safety.

Home Care . . . If the family needs support in caring for the child in the home, this could be provided by a specialist children's Home Care Assistant.

Activities . . . Alternatively, it may be agreed that the child would benefit from some activity of his or her own, giving time for other members of the family to do something different. This need for respite could be met by an "Out and About" volunteer or by one of the playschemes run during school holidays, such as the one run at Castle Hill School where activities include visits to Canon Hall, Bradley Woods and the cinema.

The Young People's Activity Team (YPAT) runs many of these social and leisure activities. They run youth clubs and various other groups mainly on Monday and Friday nights and Saturday mornings. They aim to provide one-to-one or two-to-one support for every child.

Short breaks . . . Sometimes the assessment may identify the need for day care or overnight short breaks. Families can benefit greatly from having this time away, it is by no means an admission of failure or that you don't care. Without breaks it is likely you will encounter health issues or problems yourself, by becoming exhausted, rundown or by just becoming unwell. These breaks could be provided with a family registered under the Family Link Scheme, particularly if the child is under ten years old. These families are carefully selected under the foster carers' assessment and are given regular training.

Residential respite care is also offered, as part of the breaks.

Orchard View in Mirfield, provides overnight visits and general day visits for children aged 8 to 18 years of age. Around 30 qualified and committed staff work there offering many resources including a sensory room, a sensory garden and a wheelchair swing. For more information on Orchard View please contact 01924 482101.

Another residential setting is Elm Grove in Heckmondwike. Elm Grove offers medium to long term placements for children aged 10 to 18 years of age. Around 30 qualified and committed staff offer guidance to the children, and closely follow planned routines agreed by the children and parents. Many leisure activities are offered such as sports clubs, scouts and horse riding. For more information on Elm Grove please contact 01924 325635. Crossroads is another respite service who come and will come and watch your child in the home whilst you do anything you require for various lengths of time. Saturday Morning Club at Moldgreen United Reform Church 9.30am-12.00pm is designed specifically for people with autism.

What are the limits? . . . They have limited resources, and therefore services are allocated according to service priorities. Some services are free, but others may be charged depending on the family's ability to pay.

Please contact them . . . If you would like more information about the services provided by the Children With a Disability Unit or if you would like an assessment of need, please contact the Duty Officer on: 01924 326438. Alternatively you can email them at: disabled.children@kirklees.gov.uk.

PARENT PARTNERSHIP

The Kirklees Parent Partnership Service is based at Knowl House, Knowl Road, Mirfield WF14 9RA. They can be contacted on: 01924 326646 or alternatively you can email them at: parentpartnership@kirklees.gov.uk. The service is part of the LEA. They offer confidential support and advice to parents about special educational needs. They share information about Special Needs Services and help parents to understand the education system. The partnership provides a free and confidential service.

The parent partnership has full time and part time officers, Redena Hamer and Lisa McLeod, and a part time administrator, Nicola Davies. They aim to support parents in meetings and Tribunals and will help with writing letters!

THE GREENHEAD RESOURCE UNIT

The Greenhead Resource Unit is based at 24 Greenhead Road, Huddersfield, HD1 4EN. They can be contacted on: 01484 347600. Staff are available to be contacted from 9 - 5 Monday to Friday. The emergency referral duty team can be contacted on 01924 326489. The Greenhead Resource Unit helps people with learning difficulties in Kirklees. They have a team of trained community nurses and occupational therapists etc. Ring them and ask how they might help you.

FAMILY FUND

Family Fund is a registered charity that helps low income families caring for severely disabled children. Check out their website: www.familyfund.org.uk for more information. Or contact them on 08451304542. Or at: Family Fund, 4 Alpha Court, Monks Cross Drive, York, YO32 9WN.

KIRKLEES CARERS GATEWAY

The Carers Gateway is situated at Kirklees Council Carers Gateway, 1st Floor Gateway to care, 30 Market Street, Huddersfield, HD1 2HG. They can be contacted on: 01484 226050 or by email at: carers.gateway@kirklees.gov.uk. It is a service run through by Kirklees. It aims to provide many things such as practical and emotional support to unpaid carers in Kirklees. The service offers training on moving and handling, and support and guidance for parents and carers.

The service offers the carers chance to use their resources at the centre, including the Internet, there library and audio information that they have available. The Gateway gives advice and help to carers on understanding the benefits and allowances that are available to them, including the Carer's Allowance.

They run a **Carers Emergency Card** scheme. This is an alert card that tells people you are a carer. This is useful if you should become ill or have an accident, to let emergency services know that someone may be dependent upon you. A 24 hour helpline has details of your contact details and those of the person you care for, so that alternative emergency care can be arranged for the looked after person.

THE NATIONAL AUTISTIC SOCIETY (NAS)

Set up 30 years or so ago by parents of people with autism the National Autistic Society is both a service provider and a support / lobbying organization. It runs training, conferences, a help-line, publishes booklets, raises money, awareness and fights hard to lobby for the autism cause with central and local government. It is the UK's leading charity on autism and Asperger syndrome. Its pioneering work is crucial for the future of working with and understanding those on the autistic spectrum.

The National Autistic Society can be contacted at 393 City Road, London, EC1V 1NG or on the telephone number:02078332299. Or on the helpline number:0845 070 4004 from Monday to Friday 10am until 4pm.

For more local NAS contacts and information in our area, you can contact the North East team in Newcastle: telephone 0191 226 3614. The National Autistic Society help team for the North-West can be contacted on 0161 - 946 1193. The Regional coordinator for the North regional team is Kate Spink: 0161 9987860. Our main contact is Lisa Piteathly...

Hot off the press! This came from Lisa Pitkeathly..

"I am very pleased to say that we have a new member of staff started in West Yorkshire, Dave Scowcroft. Dave has been working for the NAS Help! Team for the last few years and has now extended his hours to take on some Regional Development work. He will be taking over from me as the Regional NAS contact for West Yorkshire. I am sure Dave will be in touch with you all in the near future to introduce himself."

Lisa Pitkeathly Senior Regional Officer - North, The National Autistic Society, The Robert Ogden School, Clayton Lane, Thurnscoe, Rotherham, S63 0BG. Tel. 01709 870716 Mob 07917266339 email Lisa.Pitkeathly@nas.org.uk

Alternatively you can check out the website: www.autism.org.uk.

HSGA recommends that you consider joining the National Autistic Society with the aim of receiving membership benefits and contributing to its efforts to 'Build a brighter future for people with autism'.

NORTH KIRKLEES AUTISM SUPPORT GROUP & FRIENDS

This the autism support group set up with the families in the North Kirklees area in mind. They are very welcoming to all families and more than happy for the Huddersfield and South Kirklees families to join their activities. They have regular visits to KrazyKids playgym as well as lots of other events.

Please contact **Kath Woodhouse** on **07772534625** for further information.

WHAT IS AUTISM AND WHAT CAN WE TRY?

Autism is a developmental disorder affecting about 1 in 100 children. It is best thought of as a spectrum, with children at one end being very severely affected while at the other end the continuum shades into "normality".

It is much more common in boys than girls, possibly as many as 5-8 times more. Because it is more common in boys, the word "he" is used in the following suggestions. The difficulties in girls are often more subtle as they are thought to be more 'socially robust'.

Many children with autism show some degree of learning difficulty but because of the nature of the problem it is extremely difficult to get an accurate picture of their intellectual ability or potential. Some have strengths in certain areas or 'splinter skills' such as being exceptionally good at maths or art.

Various labels are used when attempting to define more accurately a child's strengths and weaknesses including Asperger Syndrome, Pathological Demand Avoidance, and Semantic-Pragmatic Language Disorder. These children all show some of the difficulties as described below but may or may not be given a label of ASD or Autistic Spectrum Disorder. The boundaries are difficult to define.

Each child with autism is unique and the characteristics displayed by any one child tend to change as he develops.

Professor Elizabeth Newson's definition:

- Impairment of LANGUAGE and all modes of communication including gesture, facial expression and body language and the timing of these.
- Impairment of SOCIAL UNDERSTANDING, in particular a failure of social empathy,
- Evidence of RIGIDITY and INFLEXIBILITY of thought processes.
- Onset before thirty months.

Another way of looking at autism is in terms of the "Theory of Mind". This describes the inability to mind-read or "mind-blindness". The autistic child is unable to work out what people are thinking and therefore cannot predict what they are going to do or what their motives are. There is difficulty recognizing relevant information and seeing the links between cause and effect. People with autism don't appreciate "the whole picture". There is a tendency to focus on details that ordinary children would ignore and to miss the things that others might see as important.

The links between feelings or emotions and what causes them are missing. Not only can they not appreciate what causes the feelings of those around them, but also what causes their own.

Most people with autism also have problems with **sensory processing** and have variations in hypo- and hypersensitivity to sound, sight, touch, smell, taste, balance etc. Too much stimulation can lead to "overload".

Awareness of the child's sensory sensitivity is essential as many behavioural difficulties are triggered by sensory factors e.g. changes in smell, flickering strip lighting, changes in temperature etc.

Many of the difficulties in ASD can be explained in terms of faulty sensory processing - being unable to record and retrieve information from the senses.

The other difficulties, such as rigidity of thought and liking for sameness, probably then develop over time as the child tries to cope with poor comprehension, confusion and anxiety.

Some suggestions for management:

Language

1. If your child is young, use his name to begin an instruction. He will not include himself in instructions addressed to "both of you" or "you and your brother" etc. He needs to be mentioned in person!
2. Keep language simple, with the important information at the end of your utterance. Keep your instructions as positive as possible. Many children with autism do not understand negatives and when faced with "don't...." may respond to the words they do understand and do exactly what you don't want them to do. "Put your hands down" is more effective than "don't touch ." "Walk here" is better than "don't go in the puddle".
3. If your child does not respond to a question or instruction appropriately he has probably not understood. Often the child will home in on the familiar words and disregard the confusing ones. For example: "what did you do at school yesterday?" may be answered by "yes"...an appropriate answer if he has disregarded the "what", the verb tense and the "yesterday". The use of a day-by-day calendar with drawings or, even better, photographs, of his school activities is very useful as a visual aid for talking about what he does and when. Usually the "wh" words - what, who, where, when, which etc., can be taught quite effectively . "Why?" is the hardest, but frequent explanation of cause and effect will help. Avoid asking children with autism too many "wh-" questions. They find them challenging, even stressful and questions can easily be re-worded into simple choices e.g. "Do you want orange or blackcurrant?" rather than "What do you want?"
4. Avoid ambiguity, sarcasm, and use concrete rather than abstract terminology. For example, the autistic child will respond better to "Put your Lego in the box," than to "Tidy up". "Put your coat on" is better than "Get ready to go out". Avoid "Shall we.....?" or "Would you like to....?" as they will probably say "no". Be very consistent. Give the instruction, wait calmly then repeat the instruction using exactly the same words. This gives the child time to process the instruction.
5. Teach the meaning of words such as "NO", "STOP" and "FINISHED" as soon as possible. This helps the child to learn about boundaries.

6. Use visual clues whenever possible. Sounds and words are hard to understand and are gone before the child has had time to work them out. Pictures last longer and use the visual pathway which is often stronger in autism. Photographs can be ideal for showing a child what to do or where to go. A visual timetable, i.e. a sequence of photos or drawings - will help him through the day, making moving on from one activity to the next, easier. Written notes, drawings or photographs are very useful when encouraging the older child to talk about recent events. Photographs also help him with "body image", seeing himself doing various activities, increasing his awareness of himself.

7. Remember that he has difficulty with all forms of language and may need help with understanding and using gestures such as pointing. Encourage your child to make choices by pointing, it is a very useful skill.

8. Always allow sufficient time for your child to process information. Give him time to respond and reward any attempt he makes to use gesture or sounds. He may learn to use pictures or signs to ask for things. Wonderful!! These will not hinder his development of spoken language but will encourage him to communicate.

9. The autistic child's tendency to take everything literally can lead to seemingly cheeky replies e.g. child sitting daydreaming, teacher asks "What are you doing?" child replies "sitting on a chair". A logical response from a child who takes life at face value. Just tell him clearly what he should be doing. Poor empathy also results in apparently insensitive/tactless use of language. Again the child is not being intentionally rude and will need help with understanding what he can or can't say.

Social skills and behaviour

1. The development of your child's social skills is very important. Always be looking for ways to make activities as social as possible.

Work out how things that the child does on his own can be made to involve turn-taking, simple interactions, sharing of knowledge. e.g. drawing, doing jig-saws, making Lego models, can be made into turn-taking activities, with you and your child contributing to one end product. Baking sessions are ideal for turn-taking and sharing likes and dislikes.

Gossiping, sharing interests, opinions and feelings, are the foundations of friendships and do not come naturally to people with autism. Grasp opportunities to talk about emotions.

If an incident occurs and emotions erupt, talk about what is happening, how people are feeling and why?

If your child has a tantrum, acknowledge his distress, try to understand why he is so upset and work out ways of expressing extreme emotion in an acceptable way.

People with autism are good at learning rules and need to be given clear strategies that they can use when needed.

Spend some time discouraging independence! It is good for the child with ASD to learn how to ask for help. He needs to learn not just how to ask, but who? Encourage him to ask other children, not always adults.

2. Children with autism generally do not "play" like ordinary children. They may get pleasure from collecting things like keys or batteries, lining objects up, watching the same videos over and over or turning taps on and off.

Before you try to stop him, ask yourself whether what he is doing is dangerous. If it is not, can it be allowed but time limited? Could you join in with him and try to show appreciation of the activity?

He finds it difficult to come into our world, could you go into his? You may find that this helps him to accept the presence of others.

Children with autism need time to 'be autistic' and do the things they enjoy. However, he must also learn when to stop - he must learn to recognise when people have had enough!

3. An increase in undesirable autistic behaviour such as making silly noises, inappropriate hugging, biting and refusal to co-operate are generally a sign that the task is too difficult - discourage the behaviour, make the task simpler and reward any small success.

This does not mean that all habits such as twiddling hair, rolling a pencil, flapping, masturbating etc., must be stopped. The child may need these for comfort / stress control and should be permitted unless they are anti-social, cause unacceptable disruption or danger to themselves or others. Sometimes it will be a case of "yes, you can do that, but not now." A time and place can usually be agreed.

4. Find out what your child sees as a reward. Autistic children sometimes have unusual ideas about these, so think carefully about what turns them on! Just saying "well done" or "Mummy's pleased with you" may have little meaning whereas a Smiley face sticker could work wonders.

Some autistic children will respond best to rewards such as being allowed to listen to watch a favourite cartoon, work on the computer or flick through books. The system of "First this, then that" is only effective if they want the "that".

5. If you need to change a behaviour e.g. throwing objects at you, suggest an attractive alternative such as "let's build a big tower with those bricks." Give lots of praise when the child modifies his behaviour (changes whatever it was that he was doing). Say what you are pleased with. For example: "Wow, what good building."

6. One form of imaginative play that many children with autism will enjoy is role-playing familiar situations e.g. serving in a home-made fish and chip shop or shoe shop. Act out their favourite stories - children with ASD love 'drama'.

They will learn if the activities are practical, have an obvious purpose and are FUN. If you enjoy playing with them, they will enjoy playing with you!

7. The child with autism may find sudden face-to-face confrontation, direct questions, eye-contact, physical contact or unexpected changes, not only worrying but distressing to the point of physical pain. He needs warning of change. Try to keep him "in the picture", let him know what is going to happen well in advance. For example, if he is playing happily and you need to go out, tell him ten minutes beforehand.

If his understanding is poor, show him a picture of where you are going. The child with autism is at his best when his life is predictable - if you don't help him to predict, he will try to organise it his own way. Be warned. Gain his attention when you need to tell him something but don't force him to give eye-contact, he will give it naturally when he feels comfortable with you.

8. What you may perceive as "irrational", "inappropriate" or "irrelevant" is probably highly rational, appropriate and relevant to the child. Try to see the world through his eyes, examine what has been asked of him, think carefully about whether reprimand is really necessary or whether your demands have been at fault. Whatever you are asking of the child, present it in a meaningful way.

9. Be aware of his physical well-being. Children with autism often have difficulty in expressing feelings of pain or being unwell but show it by increased aggression, rocking, head-banging or perhaps greater withdrawal. Tiredness in the afternoons is very common and it helps if less demands are made as the day progresses.

10. Reduce stimulation when possible. Too much noise, movement, colours, patterns, textures, smells etc. may result in "overload". Too many changes of colour, smell etc can also lead to distress.

11. Let your child know where he stands.... be FIRM.....be CONSISTENT. Be sure that what you want your child to do is worthwhile and within his ability range. If it is.....PERSIST, but be willing to lose. You shouldn't win every time, after all, we would like them to learn how to be flexible! If you offer choices rather than giving a command, you will get what you want nearly every time.

E.g. If your child refuses to come and sit down, instead of "sit down!" try "Which chair do you want..this one or this one?" 99% of the time they will choose one and sit down!

12. Always make sure your child knows that you love him just the way he is, that you do not feel that he has something wrong with him. He is just a bit different.

I hope some of these tips are useful. If you have some ways of reducing difficulties that you have found really useful, please let us know and we will add them to this Support Pack.

Perhaps you have ideas on dealing with haircutting or trips to the dentist! Pass them on!

GLOSSARY

The following is a glossary of the technical terms and acronyms that you may come across or are used in this support pack.

ASD- Autistic (or Autism) Spectrum Disorder

AS- Asperger Syndrome

CA - Carers Allowance. See benefits section for details of what this is.

Code of Practice - A Government document (133 pages!) which gives guidance to LEAs and schools on SEN.

CWDU - Children With a Disability Unit. See the Support section for more details about CWDU.

DLA - (Disability Living Allowance). See benefits section for details of what this is.

HFA- High Functioning Autism

IEP - Individual Education Plan. See the Education section for more details of an IEP.

KAOS - Kirklees Autism Outreach Service. See the Education section for more details of who they are and what they do.

LA - Local Authority, Kirklees.

LEA - Local Education Authority. A part of Kirklees Metropolitan Council which provides services to schools.

MLD school - A school for children with *Moderate Learning Difficulties*.

NAS - National Autistic Society. See Support section for more information on them.

PDA- Pathological Demand Avoidance

Pupil Support Service - part of the LEA, it co-ordinates much of the -services for SEN.

RP - A mainstream school which has a 'resourced provision' - a specified number of children who can access the curriculum alongside mainstream peers but are also helped by specially trained staff and therapists.

SALT- Speech and Language Therapist

SEN - Special Educational Needs. Someone needing extra or different help to someone of the same age.

SLD school - A school for children with *Severe Learning Difficulties*.

Statement of Special Educational Needs - Usually called the 'Statement'. A document which the LEA writes, following a *Statutory assessment*, which sets out the special educational needs of the child and how they are to be met.

Statutory assessment - The LEA makes an assessment of your child's needs in consultation with you, educational psychologists, health professionals, teachers and any other relevant people. This *may* lead to a *Statement of Special Educational Needs*.

YPAT - Young People's Activity Team. See support section, CWDU for more information on these.

We have a website! www.autismhuddersfield.co.uk

APPENDIX 1 - Contacts

We know that it is a very difficult time following diagnosis. It does, however, often help to speak to another parent. You can ask a fellow parent questions which it can be difficult to ask the professionals. Many of us found it helpful to contact someone who had been there before.

These contact names are members of the HSGA who have volunteered to be listed as a first contact. They may suggest that you ring someone else but don't worry about ringing. They have had a fair amount of experience by now and won't mind at all.

Kate Falkingham	President	01484 661455	coolmumdiver1@o2.co.uk
Mick Orwin	Chairperson	01484 304781	
Phil Turner	Secretary	01484 314606	pnturner@hotmail.co.uk
Geoff Saward	Treasurer	07742887648	geoffsaward@btinternet.com
Mark and Gemma Simcox	Committee	07876652793	thesimcoxfamily@btinternet.com
Sophia Saleem	Playscheme	07980 286524	sophiasaleemhsga@hotmail.co.uk
Will Penman	Diets	01484 319688	
Sheena Fitzsimmons	Librarian	01484 544147	sheenafitzsimmons@btinternet.com

Geoff Saward took over as Treasurer at the 2011 AGM. He has a son, Joseph, 13yrs, who is at Honley High School ASD resourced provision. We also welcome Mark and Gemma Simcox to the committee. They have a recently diagnosed son, William, 4yrs, and are keen to help parents of younger children in touch with each other and sharing grins and groans!

We are hugely grateful to David Woodhead for all his work as Treasurer over the years.

Who do I contact for...?

Website	Phil Turner	01484 314606
Monthly meetings	Kate, Mick, Phil or website	
Benefits	Mick Orwin	01484 304781
Newsletter	Phil Turner	01484 314606
Playscheme	Sophia Saleem	07980 286524
Education	Paul Burluraux	01484 319441
Treatments / therapies	Kate Falkingham	01484 661455
Diet etc.	Will Penman	01484 319688

We hope you find the support pack useful. Please let us know if you feel there is something we need to add or that is incorrect.

Your comments are much appreciated.

HSGA Newsletter and Membership Registration

Parents and Carers

Please complete and return this form to Phil at the address below.

This will ensure that you become a member of HSGA and receive our Newsletter.



HSGA Members Enter the names of each adult who wishes to be an HSGA member.	Name 1	Name 2	Name 3
Address 1 (We will send a newsletter to this address. If members listed above live at separate addresses and need a copy sending elsewhere, fill in the address 2 spaces)	Number and Street	Town	Postcode Telephone number
Address 2 – if any	Number and Street	Town	Postcode
Persons with autism Please give details of persons with autism	Name 1	Name 2	Name 3
Date of birth			
Relationship to HSGA member (e.g. son, granddaughter)			
Position in family (e.g. for firstborn of 3 children mark 1/3, for the second of 2 children, mark 2/2)			
Diagnosis date and type (e.g. diagnosed Dec 2008, Asperger Syndrome/ High Functioning Autism etc)			
E-mail address:			
Other details. Please give any other information you feel would help, e.g. member's skills or interests such as publicity, fund-raising etc.			
Membership. The HSGA makes no charge for membership. You may if you wish make a small annual donation, suggestion £5 . This helps cover the costs of sending out the newsletter, maintaining the website, and is for a whole family. You may send a cheque with this form or see a committee member for more details. Please tick the box if you would like the newsletter to be emailed to you which helps keep the cost down!! <input type="checkbox"/>			

Please return this form to: **Philip Turner, 4 College Street East, Crosland Moor, Hudds HD4 5DN**

HSGA Newsletter and Membership Registration



Professionals

We feel that it is important that our newsletter reaches professionals because it will inform you of what we are doing and perhaps help to highlight some of the recent developments in autism.

It meets one of the objects of our charity to spread awareness of autism and so we will send out our newsletter free of charge to professionals who wish to receive it on that basis. However, at a current cost of 50p-60p per newsletter sent out, we ask that, if possible, people should make a donation to help cover the cost. An annual donation of £5 would be much appreciated. **Surely we can send it to you by email...** in which case there is no cost.

Please complete and return this form to Phil at the address below.

This will ensure that you become a member of HSGA and receive our Newsletter.

Name	Building/No/Street	Town	Postcode Telephone number
Professional title/status			
e-mail address:			
Please tick the box if you would like the newsletter to be emailed to you <input type="checkbox"/>			
Please give the names and addresses of any other professionals who may wish to receive the HSGA newsletter			
Name & status	Building/no/street	Town	Postcode Telephone number
Name & status	Building/no/street	Town	Postcode Telephone number
Other details/additional comments (please include any special interests or specialist skills you have)			

Please return this form to: **Philip Turner, 4 College Street East, Crosland Moor, Hudds HD4 5DN**