

April
2010

Information for parent- carers of ...

DISABLED CHILDREN AND
CHILDREN WITH SPECIAL NEEDS

Maidstone
& Malling

Maidstone
Carers
Project

Tel: 01622 685276

INTRODUCTION

If you are a parent carer it is important to know what help is available. It is not always easy to know where to go to find this information and you will probably have little time and energy to seek it out.

The aim of this guide is to provide information which will act as a signpost to support and services in the Maidstone and Malling area for children under 19 years with disabilities or special needs and their families and carers.

It has been compiled by Maidstone Carers Project with the valuable help of local carers who volunteered their time and experience.

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West Kent

HELP AVAILABLE FOR YOUR CHILD

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HELP AVAILABLE FOR YOUR CHILD

1. HEALTH SERVICE

Your GP and Health Visitor – your GP will be able to help you with medical needs. You can contact your Health Visitor, who will be able to give practical advice when visiting you at home, by telephoning your GP's surgery. Your GP will be able to refer you to a range of other services:-

- **District Nurse** to help with practical tasks involved in nursing a child at home.
- **Diana Community Children's Nurse** to help with the practical tasks involved in nursing a child at home who has a life threatening or life limiting condition.
- **Occupational Therapist Home Assessment Team** to help you and your child manage daily tasks.
- **Physiotherapist** to provide treatment and advice to relieve pain and increase mobility.
- **Community Psychiatric Nurse** to give you advice if your child has mental health problems.
- **Community Paediatrician** to give advice and support if your child has special educational needs and in Statutory Statementing of their needs.
- **Community Paediatric Diabetes Specialist Nurse** to provide support to carers and an ongoing integrated package of care through transition to the young adult clinic.
- **Specialist ADHD Nurse** [Attention Deficit Hyper Activity Disorder] promotes the wellbeing and life chances of children and young people with ADHD and associated difficulties.
- **Special Needs Team** work with children with special and complex needs from birth to age 19 years and their families
- **Speech & Language Therapist** for children who have difficulties with interaction, understanding and use of spoken language as well as with eating, drinking and swallowing problems

- **West Kent Children's Hearing Service** provide paediatric audiology diagnostics, assessments, ear mould impressions, fitting hearing aids & offer advice and support
- **Orthoptist** provides a vision screening service for pre-school children.
- **Community Dental Care** can be provided for children with special needs at clinics.
- **Paediatric community dietician** for advice and support on food and nutritional issues
- **The Community Children's Nursing Team** for children who have life threatening or life limiting illnesses or require nursing on being discharged from hospital
- **Continence Adviser** to give you advice and practical help if your child has urinary or bowel problems. [For children 4 years and above].

For further information on the services listed above contact The Patient Advice and Liaison Service [PALS]. PALS also provides information, help and advice on all health matters, treatments and support groups.

Tel: 01622 224960

PALS also help if you are having difficulties with health services

- Maidstone Hospital Services **Tel: 01622 224960**
- Community Services **Tel: 0800 085 0850**
- Mental Health & Learning Disability Services **Tel: 0800 587 6757**
- Ambulance Services **Tel: 01622 740348**

School Nursing Service - give expert health advice and help on healthy eating and exercise, behavioral problems, difficulty settling in school, bed-wetting etc. Contact the service through your child's school or local clinic.

Maidstone **Tel: 01622 226061** or Malling **Tel: 01732 221161**

Maidstone Multi-Agency Single Point Assessment Team – works in partnership across health, education and social services to support children, teenagers and their families who are experiencing emotional/behavioral and mental health problems. Contact the School Nursing Service as above

Tel: 01622 226061 or your GP

Carers Direct – NHS choices website www.nhs.uk/carersdirect provide information, advice and support for carers or call free from 8am-9pm Mon-Fri or 11am-4pm weekends **Tel: 0808 802 0202**

West Kent Care Call – free telephone support service for people over 16 with long term conditions, run by experienced registered nurses call Health Coaches
Tel: 0800 169 1824

NHS West Kent – in partnership with **Maidstone Carers Project** is running a Pilot Project for ‘Better Support for Carers in the NHS’ [until March 2011]. Carer Support Workers will be working with the College Practice and Hospital sites. If you are a patient at College Practice or you or the person you care for is going into hospital **Tel: 01622 230729**

2. SOCIAL SERVICES

Additional support in caring for your child.

Who to contact? – the first point of contact would be to ring **01622 605609** or the 24 hour Social Services Call Centre number **0845 824 7100** who will take some details from you and, if appropriate, forward them to the Children & Family Team. Once you are known to the team your Social Worker will give you a direct number. If you have an emergency outside office hours you can also **Tel: 0845 762 6777**.

What they should do – a Social Worker from the Children & Family Team will carry out an assessment of your child. The Social Worker will visit you at home to talk about what support and services you think you need. Try to prepare for the visit by thinking about the things which would help you and your child. It may be a good idea to make notes and write down any questions you have.

If your child is assessed as requiring a service, the kinds of services that may be offered :-

- advice on benefits and finance
- practical advice, guidance
- social, cultural or recreational activities
- help in the home
- range of respite care [care of your child while you take a break] and activities
- aids, equipment and grants for housing repairs and adaptations [see 8. EQUIPMENT].
- Referral on to other agencies

Children’s Disability Register – is a confidential computerised database containing details of children who have a disability. It is voluntary: you have the choice whether or not to register your child **Tel: 08458 247 247**

Direct Payments – people assessed as needing services or support [including carers] can choose to be given money to arrange this for themselves instead of receiving services arranged by their child's social worker. This is called a **Direct Payment**. To find out more contact the **Direct Payment Support Scheme Tel: 0845 365 0210**

For a free booklet '**A Parents Guide to Direct Payments**' [0202]
Tel: 0845 602 2260 or download from www.dcsf.gov.uk

Deaf Services Childrens & Families Team – Tel: 01233 898515
Minicom 01233 898513 Fax: 01233 898514

Also see HELP FOR YOU AS THE PARENT/CARER 15. SOCIAL SERVICES

3. THE UNDER 5s

Maidstone Child Development & Therapy Centre – provides a range of services for children from 0-5 years. Following an assessment and after discussion with you, your child may be offered a range of out-patient therapies or may be asked to attend the Centre in Union Street where there is an Early Intervention Team and a specialist Health Visitor for children with special needs. Referrals are made via the hospital, your GP, Health Visitor or Pre School adviser **Tel: 01622 225870**

Kent Portage West [home teaching for 0- 5 years] – a trained Portage Home Visitor will work in partnership with parents. Portage focuses on a child's achievements, builds on them and breaks down new activities into small steps. **Tel: 01892 633252**

Toddler Groups/Playgroups/Nurseries for under 5s – toddler groups are run usually on a weekly basis for children and their parents. Many in Maidstone are run by local churches or by mothers themselves. Playgroups and nurseries open for a few hours one or more times a week. There will be a charge.

Kent Children & Families Information Service – for the most up to date list of registered early years and childcare provision anywhere in Kent and information on provision which would best meet your child's disability or special need. **Tel: [freephone] 0800 032 3230**

4. EDUCATION

If your child has special educational needs they will require extra help and support to get the most out of the education system. The Department for Education and Skills produce a leaflet '**Special educational needs – a guide**

for parents & carers' [00639-2008] Tel: 0845 602 2260 or download from www.teachernet.gov.uk/publications. Contact a Family have free leaflets '**Special Educational Needs - England**' and '**The NHS and Caring for a Disabled child**' Tel: 0808 808 3555 or download from www.cafamily.org.uk

Having your child's needs assessed – planning education for children with special needs can start as early as two. You can ask Kent County Council Education Department for an assessment or it can be requested by a professional in contact with your child eg GP, Health Visitor or Community Consultant Pediatrician.

In School – sometimes a child's special educational needs are not identified until they are in school. **Assessments can be carried out at any time during a child's school career.** Two information booklets '**What is a Statutory Assessment?**' and '**Information about the Statutory Assessment Process**' are available from Special Education Services or Partnership with Parents **Tel: 01622 350640** If you have any concerns that your child's needs are not being met, discuss this with the school.

A range of additional support can be provided in mainstream schools called School Action and School Action Plus. If your child's needs cannot be met within the school the assessment will determine the level of support needed. There are special needs units and schools which cater for children with different disabilities and special needs if considered appropriate following an assessment.

For further information contact **Special Education Services Mid Kent Area Office Tel: 01233 898639**

The Kent School Database – provides an online directory of Kent LA (Local Authority) schools. www.kent.gov.uk/education-and-learning

Leaving School – if your child has a 'Statement of Special Educational Needs' it will be revised each year. After fourteen years of age the review must include a Transition Plan in order to prepare for post sixteen education. The Statement ends when your child leaves school.

The transition plan not only covers post-school provision but includes on-going school provision. Transition planning must also include, in conjunction with Health and Social Services:

- What the young person needs to become more independent
- What practical help or adaptations may be needed at home
- What special health needs require on-going support
- What the young person and family want.

The Connexions Service is responsible for overseeing the delivery of this plan.

Connexions – can advise on further education and employment opportunities as well as benefits and housing. **Tel: 01622 753360 National helpline: 8am-2pm Tel: 0808 001 3219 www.connexions-direct.com**

Contact a Family – has a good leaflet “*Preparing for Adult Life and Transition*” **Tel: 0808 808 3555** or download available from www.cafamily.org.uk/transition

Transition to Adulthood – www.kent.gov.uk has information about ‘Transition in Kent’ including the ‘Transition Strategy’ document, Handbooks for Parents and ‘*The move to Adulthood – Planning for the Future*’ (easy read version).

Five Acre Wood Post 16 Unit – has a purpose-built suite based within Aylesford School Sports College **Tel: 01622 717341 www.five-acre.kent.sch.uk**

Kent Children & Families Information Service – provides free confidential, impartial, information advice to parents/carers about Early Years Education and Childcare services for 0-19 years Mon-Fri 9-5pm **Free phone 0800 032 3230**

Skill: Information Service for Students with Disabilities provides information and advice on all aspects of further and higher education for students with disabilities **Free phone 0800 328 5050 www.skill.org.uk**

Mid Kent College – runs mainstream courses that young people with a disability or special need could attend. They also run courses specifically designed for students with a range of learning difficulties. For further information **Tel: 01634 402020 www.midkent.ac.uk**

Hadlow College – offer a wide range of courses suited to students with learning difficulties and/or disabilities **Tel: 0500 551 434**

Kent Adult Education – offer courses that can help improve reading, maths, computing & communication skills including Managing Money, Healthy Lifestyles, Community Living & Work Skills **Tel: 0845 606 5606 www.kentadulthoodeducation.co.uk**

HELPFUL ORGANISATIONS ON EDUCATION

LOCAL

Partnership with Parents Helpline – provides impartial advice and supports parents/carers of children with special educational needs and disabilities to be fully involved in their child's education. They offer confidential telephone helpline guidance and information, and face to face support.
Tel: 01622 755515

Partnership with Parents can provide information on the 'Aiming High for Disabled Children' [AHDC] transformation programme for disabled children's services. This will enable parents to be fully informed about local and national developments, to discuss issues and ensure their views inform policy and practice. For more information **Tel: 01622 350640** www.kentppn.com

Dandelion Time – works with children struggling with emotional and behavioural difficulties, who have withdrawn or been excluded from school, by engaging the whole family in a programme of craft and farm based activities. They aim to help children to re-engage positively at school, and at home, by improving their sense of self-worth, and awakening their creative potential. Referrals are made through GPs, Social Services and Education.
Tel: 01622 814001 www.dandeliontime.org

NATIONAL

Advisory Centre for Education (ACE) – information and advice for parents including exclusion from school, bullying, special educational needs and school admission appeals **Tel: 0808 800 5793** www.ace-ed.org.uk/index.html

Independent Panel for Special Education Advice – independent advice to parents who are uncertain of their child's special educational needs. Can also help with appealing to the Special Educational Needs Tribunal, including representation when needed and free second professional opinions.
Tel: 0800 018 4016 www.ipsea.org.uk

Network 81 helpline – education advice for parents of children with special needs. Mon-Fri 10-1pm. **Tel: 01279 647415 / 0845 077 4055** www.network81.org

Centre for Studies on Inclusive Education – information on educating children with special needs in mainstream schools. **Tel: 0117 328 4007**
www.csie.org.uk

Parents for Inclusion – promotes inclusive education with appropriate support in mainstream schools **Tel: 0207 735 7735** Helpline run by parents Mon to Wed 10 – 3pm **Freephone Tel: 0800 652 3145**

5. HAVING FUN

Hotfoot Plus – Summer and Easter holiday play schemes aim to integrate children with special needs aged 5 – 15 years, who live or go to school in Maidstone, into the Maidstone Borough Council Hotfoot Play Scheme by providing appropriate one-to-one support. Contact Maria Cox
Tel: 01622 746539 or the Youth & Development Team **Tel: 01622 602222.**

Malling Summer Playscheme Plus – provide fun activities for children with special needs children aged between 4 -18 **Tel: 01732 876166**
www.tmbc.gov.uk

Beacon Church [Shepway] – provide activities for disabled children.
Tel: 01622 661560

Infozone – run an inclusive, all abilities, youth club on Tue 6 - 8.30pm and Thu 4 - 7pm which includes activities such as arts and crafts, music, table tennis, pool, life skills enhancing confidence and social skills.
Tel: 01622 755044

MENCAP – for children who have learning/physical disabilities. Pre-school playgroup 1yr– school age. Junior Gateway Club under 16 yrs, Senior Gateway Club over 16 yrs. **Tel: 01622 670464**

Arrow Riding Centre for the Disabled Dartford – open 6 days a week for lessons to all ages and varied disabilities. May be a waiting list.
Tel: 01322 294390

Riding for the Disabled Chalk Down Group Staplehurst – **Tel: 01622 850310**

Leybourne Grange Riding Centre for the Disabled Leybourne
Tel: 01732 872844

Tonbridge & Malling Special Needs Club – a disability multi-sports club meets twice monthly at Larkfield Leisure Centre on Saturday evenings from 5-7pm. Entry for carer attending is free **Tel: 01622 719345**
www.larkfieldleisure.co.uk

Jumpers Rebound Centre Gillingham – trampolining private coaching available for special needs children **Tel: 01634 855507** www.trampoline.co.uk

Maidstone Leisure Centre Mote Park Maidstone – free swimming for special needs child [in receipt of Disability Living Allowance] and carer and cost reduction for other facilities when purchasing centre membership at £4.95 a year [proof of ID required] **Tel: 0845 155 2277** www.maidstoneleisure.com

D-Max Club – a sports club for children and young people with a variety of disabilities [siblings welcome]. Astor of Hever Sports Centre in Oakwood Park Thu 5.30-7pm and Maidstone Leisure Centre Mon 5.15 - 6.45pm. £15 for six weeks membership **Tel: 01622 602222** www.digitalmaidstone.co.uk/sports

Kent Youth ME2 Project – brings disabled and non-disabled young people together to enjoy youth club activities **Tel: 01634 281841**
www.kentyouth.org

Pegasus Gymnastics Club – fully equipped facility catering for children aged 4 months and upwards. Children with disabilities are integrated within main stream classes. Available for private bookings **Tel: 01622 737170**
www.pegasusgc.org

VSU Youth in Action – fun clubs in Maidstone for disabled children & weekend clubs contact Isobel Standen **Tel: 01732 362699**

Zereth Active Zone – a specially adapted gym for special needs youngsters under 18 Boughton Lane in Maidstone. Weekdays 4 - 6pm Sat 10 - 12am.
Tel: 01622 749564

REPLAY – advise on all forms of play for children from 0-16 years including children with disabilities **Tel: 01732 817892**

The following organisations grant wishes for children with a life threatening illness:

- Make a Wish Foundation **Tel: 01276 405060**
- The Starlight Foundation **Tel: 0207 2622881**

6. HOLIDAYS

Most travel agents can offer information and advice about the suitability of a holiday location for children with special needs. Useful organisations are listed below.

Tourism for all – free advice service to families with disabled members. Hotel reservation service and information leaflets **Tel: 0845 124 9971**
www.tourismforall.co.uk

Break – provides special care services for children and families with special needs including holidays and respite care, children's homes, adult day care and residential assessments for families in crisis **Tel: 01263 822161**
www.break-charity.org

Family Holiday Association [FHA] – specialize in providing holidays for families and children in need **Tel: 0207 436 3304** www.fhaonline.org.uk

Enable Holidays – provide package holidays for disabled people, their families and friends **Tel: 0871 222 4939** www.enableholidays.com

Scout Holiday Homes Trust – you do not have to be Scout/Guide. Inexpensive holiday camps **Tel: 0208 433 7290**
www.scoutbase.org.uk/hq/holhomes

React – provides assistance to families caring for children with a potentially terminal illness, including funding for medical and domestic equipment and 8 mobile holiday homes on 6 sites in the UK. **Tel: 0208 940 2575**
www.reactcharity.org

Dave Lee's Happy Holidays – provides a free holiday for the whole family where one child has a serious illness or disability **Tel: 01227 728240**
www.happyholidays.moonfruit.com

National Holiday Fund for Sick and Disabled Children holidays for chronically or terminally ill children, and temporarily or permanently physically disabled children, aged between 8-18 years. **Tel: 01493 731235**
www.nhfcharity.co.uk

7. HOUSING:

ADAPTATIONS TO MAKE LIFE EASIER

Social Services Occupational Therapy Service – make a full assessment of needs which could include major alterations to the home eg lifts, special showers. **Tel: 01622 691640** [Maidstone] or **01732 525000** [Tonbridge & Malling]

In Touch Home Improvement Agency – can give advice and help with grant aid for adaptations to the home [owner occupiers and private tenants only].
Tel: 01732 525520

8. EQUIPMENT

Health Services Occupational Therapists – [ask your GP] can make an assessment of your child's difficulties and advise you on appropriate equipment and how to use it. They also have a free loan service for small personal pieces of equipment **Tel: 01622 729000 Ext: 4301**

Home Equipment Loans – [Helpstore] provides equipment to people being nursed at home following discharge from hospital or being seen by a District Nurse, GP or therapist. This is a free service. Referrals are made through a health professional.

REMAP [Technical Equipment for Disabled People] is a charity which provides custom designed aids for disabled people often helping with difficulties which cannot be solved by standard commercial equipment. This is a free service. **Tel: 0845 130 0456**

Euro Mobility – Mid-Kent Shopping Centre, Castle Road, Allington, Maidstone have equipment/aids to view. **Tel: 01622 755744**

4 Mobility – Medway Street, Maidstone have a range of mobility and home/health products [free parking on site]. **Tel: 01622 754800**

Charterwood Mobility – Notcutts Garden Centre, Maidstone stock a wide range of mobility products **Tel: 01622 730519**

County Lifestyles Mobility – 1 Harrow Cottage, Horseshoes Lane, Langley. Mobility vehicles and equipment. Home visits and advice to help save you money on equipment **Tel: 01622 863300**

The Disabled Living Foundation – gives advice about aids and equipment **Tel: 0870 603 9177** www.dlf.org.uk

RADAR – campaigns to encourage change for full inclusion in society for disabled people **Tel: 0207 250 3222**

The Wheelchair Service [Preston Hall Hospital] – provides suitable wheelchairs and maintenance or replacement of equipment as required. To get the service, ask a professional eg a doctor, health visitor or therapist to make a referral. **Tel: 01622 713018**

Easy Rider Scheme – offers assistance with funding for aids such as wheelchairs and buggies for financially disadvantaged children under 19 years. **Tel: 0207 428 8100**

South East Driveability – can give practical demonstration of special car seat to aid access to car **Tel: 01622 795719**

Ability Net – is a national charity offering professional expertise in the use of computers for people with all kinds of disability. **Freephone 0800 269545**
www.abilitynet.org.uk

Free Nappies – if your child, because of disability or special needs, is still wearing nappies past the age of 4 years, you may be entitled to receive some nappies free of charge following assessment. Contact your Health Visitor or School Nurse.

Stars – Kent Association for the Blind runs a toy, games, books and video library on the last Friday of the month 10-12pm **Tel: 01622 691357**
www.kab.org.uk

VAT Exemption – gadgets and equipment designed solely for people with disabilities are zero rated for VAT. The supplier should have details but if not, for free booklet [701/7] Tel: **0845 302 0203**

9. TRANSPORT/ GETTING OUT & ABOUT

LOCAL TRANSPORT SCHEMES

Kent Karrier – a community bus for people within the Maidstone area who have difficulty using bus services [due to mobility problems or distance from a bus route in rural areas]. This service collects you from home for journeys to the town centre and hospital etc. It operates in different areas on different weekdays.

Dial-a-Ride – a door to door service in specially adapted vehicles for people who use a wheelchair. For journeys only within the Maidstone area. For both of these services there is a £5 per annum membership fee and a subsidised charge for each journey. Carers/companions can travel with a member and only pay journey cost. **Tel: 01622 605349**

Compaid Trust run a similar service for the Tonbridge & Malling area.
Tel: 0845 094 4629

Volunteer Transport Scheme – if your child is unable to manage on a bus this service can provide a volunteer car driver who will pick you and your child up from home and take you wherever you need to go. There is a mileage charge, the Transport Scheme can tell you the current rate. **Tel: 01622 756662** between 9am-4pm Mon-Fri.

Malling Volunteer Centre Transport Scheme – **Tel: 01732 843346** between 10am-1pm Mon-Fri

Hospital Transport – is for people medically unfit to travel to hospital by other means. Arrangements can only be made via the Primary Care Booking Service
Tel: 01622 791472

Hospital Fares – people on Income Support may get help with fares or other travel expenses when attending hospital. Ask for a claim form at the Hospital Administration Office.

British Red Cross Society – can provide an ambulance with two trained crew members for people needing this type of transport [eg if needing to lay down]. £1.60 per mile for journeys over 50 miles plus a call-out charge of £160.
Tel: 01233 642064

Blue Badge Scheme – if your child is over 2 yrs and has serious mobility problems or is registered blind and has regular use of a car you may be entitled to a special permit for easier public parking. **Tel: 01622 605020**
www.bluebadge.direct.gov.uk

Exemption from Vehicle Road Tax – if your child is 5 years or older and receiving the higher level of the Disability Living Allowance [mobility component] you can apply for this exemption if you have a car that is only used to transport your disabled child. **Tel: 0845 712 3456**

Motability – a scheme to help pay for a car, hire or hire purchase. Your child must be 5 years or older and be receiving the higher level mobility component of the Disability Living Allowance **Tel: 0845 456 4566 Minicom 01279 632273**

National Key Scheme – for toilets for disabled people enables key holders to unlock all disabled toilets in the scheme. Keys cost £3.50 contact **RADAR**
Tel: 0207 250 3222

Changing Places [Maidstone Gateway] – fully accessible toilets for disabled people with complex and challenging needs. They include a hoist, height-adjustable changing bench and peninsula toilet for maximum access. Open weekdays 8.30-5.30 [Thu to 7pm and Sat 9-1pm]. www.changing-places.org

RAIL TRAVEL

Disabled Persons' Railcard – This is a National railcard that entitles you and your child to travel at a reduced rate. **Tel: 0845 605 0525**

South Eastern Trains – assisted travel arrangements for disabled people.
Tel: 0800 783 4524 or 01732 770099

10. MONEY

Welfare Benefits – if you are on a low income there may be a range of benefits to help. These are called means-tested benefits. There are also non-means-tested benefits available for some people because of their care needs and for some carers. See **HELP FOR YOU AS THE PARENT/CARER** 16.
MONEY FOR YOU. To find out if your child might be entitled to any of these benefits get leaflets from your local office. Job Centre Plus **Tel: 0845 604 3719**

Non-means-tested Disability Living Allowance – which has a care and a mobility component. For information and forms about disability benefits contact **Disability Benefit Enquiry Line Tel: 0800 882200**

Means tested – if you are on Income Support and your child is entitled to Disability Living Allowance or is registered blind you may be able to claim the **Disabled Child Premium**. New claims are processed via Child Tax Credits

If you are on Income Support and have a disabled or seriously ill child you may be able to get a **Community Care Grant** or a **Budgeting Loan** to pay for certain items.

If you are unsure whether to apply for any of these benefits or would like help to complete the forms you can get help from **Maidstone Carers Project**
Tel: 01622 685276 or **Citizens Advice Maidstone Tel: 01622 688133** open 10am-4pm Mon-Fri or **Citizens Advice Malling Tel: 01732 440488**

Council Tax Disability Reduction – you may be able to get this if you need extra space in your house because of your child's disability. Contact the Council Tax Section for your area - Maidstone Borough Council
Tel: 01622 602000 or Tonbridge & Malling Council **Tel: 01732 844522**

Maidstone Gateway - a one stop shop [next to The Mall Chequers Centre] for Maidstone Borough Council services as well as information and advice about housing, benefits, Kent Adult Social Services, blue badge and travel voucher applications, internet access etc. Open from 9-5 Mon-Fri.

Royal British Legion – offers advice and financial help to any member of the ex-service community who is in need [this includes dependants].
Tel: 01622 790566

Soldier's Sailors' Airmen and Families Association [Forces Help] – helps on a confidential and practical basis, Service and Ex-Service men and women and their dependants to confront problems and cope with hardship.
Tel: 01622 792929

The Family Fund – this is a government fund independently run to help families who are caring for a severely disabled or seriously ill child under 16. For information **Tel: 0845 130 4542**

LEAVING MONEY FOR YOUR CHILD

“Wills & Trusts: leaving money to someone with a learning disability” – is a helpful free booklet produced by **MENCAP** **Tel: 0207 696 6925** or download at www.mencap.org.uk

11. HELP IN AN EMERGENCY/OUT OF HOURS

Medical Help – If you are worried that your child is seriously ill contact your GP surgery and a message will tell you what to do.

If your child chokes – encourage them to cough. If this fails, lean them forward and give them 5 sharp blows between the shoulder blades using the heel of your hand. If you are unable to help or if they have collapsed **dial 999 immediately**.

Kent Search & Rescue – suggest when you change the clocks each year you also take a photo of your child so that if they should wander off, a recent photograph makes it easier to find them and get them home safe. You can also complete a 'Life History Questionnaire' form to record information such as physical description, medical history and particularly information about where the person is likely to wander to, so you can provide it to the Police in the event of an emergency **Tel: 01843 832 995 www.ksar.co.uk**

Kent Fire & Rescue Service – offer home fire safety advice and if required installation of a free smoke alarm **Tel: 0800 923 7000**

Kent Carers Emergency Card Scheme – carers can register for a free card which, in the event of an emergency [e.g. sudden illness or accident] will alert others to their caring role. The card has a 24 hour call centre number to ring and an unique identification number which will enable the call centre to activate a pre-arranged care plan. To find out more or to register contact Maidstone Carers Project **Tel: 01622 685276 www.kentcarersemergencycard.org.uk**

District Nursing Service – if you need help or advice from your district nurse contact your local GP Surgery

Chemists – to find out which chemist is open out of usual hours call NHS Direct **Tel: 0845 4647**

Social Services – for urgent advice that cannot wait until the next working day contact **Out of Hours Service Tel: 0845 762 6777**

NHS Direct – is a telephone service staffed by nurses, giving confidential healthcare advice and information 24 hours a day **Tel: 0845 4647**

Gas smell or suspected leaks - **Tel: 0800 111 999**

Dentaline - If you require emergency out of hours dentistry or are not registered with a dentist **Tel: 01634 890300**

Samaritans – provides a 24 hour listening service for anyone needing to talk to someone in confidence **Tel: 0845 790 9090**

12. IF THINGS GO WRONG

If you have any problems with a service you receive or disagree with a decision that has been made by a professional, there are formal ways for you to try and get things changed.

National Health Service – to find out how to complain about a particular service or professional contact a Customer Service Officer at NHS West Kent **Tel: 0800 085 0850**

Social Services Customer Care – ask for an information leaflet about their complaints procedure. **Tel: 01233 652165**

Education – if you are not satisfied with decisions made about your child's education and their Statement of Special Education Needs you can appeal.

Department for Education and Skills – has a free leaflet '*Special Educational Needs Tribunal – how to appeal*' [ref: TRI 022] now out of print but available from Maidstone Carers Project **Tel: 01622 685276** or to download at www.teachernet.gov.uk/publications

If you want more information or help to make a complaint about the above or other services the following local organisations can help:-

Patient Advice and Liaison Service [PALS] – all aspects of primary care within the community. **Tel: 0800 085 0850**

ICAS [Independent Complaints Advocacy Service] – provides support to people if they have a complaint regarding their National Health Service treatment **Tel: 0845 600 8616** www.seap.org.uk/ICAS

Kent Health Watch - will help you find the right place to make comments or raise concerns about health and social care. It is run by KCC in partnership with the NHS and provides another route by which people can make their voice heard. The service operates 24hrs a day, seven days a week.
Tel: 0845 824 7103

Advocacy Partners – advocacy support for people with learning disabilities 14+ in the Maidstone area. Advocates help people with issues or problems speak up for themselves or will speak on their behalf **Tel: 0203 355 7141**

The Equality and Human Rights Commission – provides information and the right to equal treatment and what to do about discrimination on the grounds of disability, age, gender, religion or belief, sexual orientation or race.

Helpline Tel: 0845 604 6610

The Disability Discrimination Act – gives disabled people new rights, in the areas of employment, getting goods and services and buying or renting land or property. A brief guide to the act is available.

Tel: 0845 604 6610 Textphone 0845 604 6620

The Care Quality Commission – if you have a complaint or concern about care standards in a residential/nursing home or about a care agency coming into your home **Tel: 03000 616161**

Action for Children – deals with complaints made by, or on behalf of, children against Social Services or the Education authority **Tel: 0800 413688**

Community Legal Services Directory helpline – gives details of local solicitors, advice agencies and information providers committed to providing a high standard of service **Tel: 0845 608 1122**

Citizens Advice Maidstone – Tel: **01622 752420/757882** Money Advice **01622 751788**, Welfare Benefits **01622 688133**, Housing **01622 674032**

Citizens Advice Malling – Tel: **01732 440488**

Maidstone Carers Project –Tel: **01622 685276**

HELP FOR YOU AS THE PARENT-CARER

13. SUPPORT

Maidstone Carers Project – provides information about local services and support for anyone caring for a child, family member or friend in the Maidstone & Malling area. Information about benefits and help to fill out forms. Carers groups offer mutual support and friendship. A regular Carers Forum enables carers to talk directly to service providers and planners. A free confidential listening ear. Free Carers Emergency Card. Free Caring with Confidence Courses for carers **Tel: 01622 685276** www.vam-online.org.uk/carersproject.asp

Maidstone Carers Project & NHS West Kent are working in partnership on a pilot project – please see Section 1. HEALTH SERVICE.

Maidstone Children's Development and Therapy Centre Support Group – The Centre at 188 Union Street Maidstone helps children aged under 5 years.

Many services are provided at the Centre. The Support Group is open to all parents with a special needs child under the age of five years who has been referred to the Centre. Contact Mary Board or Jenny Davis **Tel: 01622 225870**

Home-Start – volunteers visit the home for a few hours each week to give practical, friendly support to families with at least one child under 5 years.
Tel: 01622 675879

Kent Partnership with Parents – offers a free training programme to enable parents to understand the theory of participation and develop the skills to participate confidently **Tel: 01622 350640** www.kentppn.com

Local Self-Help/Support Groups and other help – self-help and support groups provide a chance to meet other parents, share experiences, mutual support or exchange information.

Beacon Centre – provides help for families in need in the Shepway, Mangravel, Parkwood and Senacre areas. Services include; advice centre, computer skills centre, household store as well as community workers to support students and offer help to families. **Tel: 01622 661560**

Bower Grove Parent Support Group – this group is also open to parents of special needs children, including ASD Spectrum in mainstream schooling. Detailed information about **all aspects of caring for a child with special needs** can be found on their website in **The Maidstone Resource Directory**. Contact Jo Cousins **Tel: 01622 726773**
www.bower-grove.kent.sch.uk/parents-support

Children and Adults with Learning Difficulties – contact Maidstone MENCAP **Tel: 01622 670464**

Eating Disorders - local support group meets 2nd & 4th Monday each month at Priority House. Contact Kathy Maclean **Tel: 01634 270522** or Tina Emery **Tel: 01634 811395**

The Fathers Club – support in Maidstone for fathers and grandfathers of children with autism. Contact John Franklin via the Kent Austistic Trust **Tel: 01634 405168**

Kenward Youth Services – [previously Grey Zebra Youth Project] information, advice and support for families coping with substance misuse 9-5 helpline **Tel: 01622 816081**

Find a Voice – supports people with severe communication difficulties and parent/carers. Information and advice about communication aids. Free resource library www.findavoice.org.uk

Kent Autistic Trust [Family Support] – a family support officer can provide information and support on diagnosis, education and behaviour management. A **Parents/Carers Support Group** meets every other month for coffee, a chat and information at The Salvation Army Hall in Maidstone. For further details, contact Jo **Tel: 01634 405168** www.kentautistictrust.com

Kent Association for the Blind – helpline **Tel: 01622 691357** www.kab.org.uk

Maidstone ADHD Support Group – Aylesford contact Kymm Tornado
Tel: 01732 841675

Maidstone Carers Support Group – for all carers contact Barbara Hagan
Maidstone Carers Project **Tel: 01622 685276**

Maidstone Parents' Voice – enables parents and carers to support their children by keeping informed, sharing ideas and views and developing links with parent/carers support agencies **Tel: 07787 295 405**

Meadow Children's Centre – run a programme of events and groups for children and parents in Furfield Close, Parkwood **Tel: 01622 699900**

Sunshine Children's Centre – run a programme of events and groups for children and parents in Stagshaw Close, Maidstone **Tel: 01622 752285**

Scope Response [Cerebral Palsy] – **Tel: 0808 800 3333** www.scope.org.uk

Sense Kent [Deaf/Blind and Rubella Association] – **Tel: 01622 831345**
www.sense.org.uk

Work focused support for carers – a Jobcentre Plus voluntary scheme providing advice & support for carers preparing to work **Tel: 0845 604 3719**

Kent Local Involvement Network [LINK] – independent network of individuals & community groups working together to influence and improve local health & social services **Tel: 07976 596709**

NATIONAL SELF HELP/SUPPORT GROUPS AND OTHER HELP

Carers UK – a whole range of leaflets/booklets are available. Also information/regular newsletter for young carers.

Freephone Tel: 0808 808 7777 www.carersuk.org.uk

Carers Direct – **NHS choices website** www.nhs.uk/carersdirect provide information, advice and support for carers or call free from 8am-9pm Mon-Fri or 11am-4pm weekends **Tel: 0808 802 0202**

Cerebra for Brain Injured Children & Young People provides specialist information to anyone concerned with brain injury or brain related conditions; (medical, educational, legal, therapeutic, welfare rights, etc.)
Freephone 0800 328 1159 www.cerebra.org.uk

Contact a Family [Help and Advice] – links families together and encourages mutual support between parents. It maintains national and regional databases of parent support groups and publishes a range of very helpful factsheets. Freephone helpline 10-4 Mon-Fri **Tel: 0808 808 3555** www.cafamily.org.uk

Steps – information & support for families affected by hip dysplasia and other lower limb deficiencies **Tel: 01925 750271** www.steps-charity.org.uk

Young Minds Parent's Information Service – a national children's mental health charity, providing information and advice for anyone with concerns about the mental health of a child or young person **Freephone Tel: 0808 802 5544**
For Mind's useful leaflet "***Understanding Childhood Distress***".
Tel: 0845 766 0163 or 'read only' version on www.mind.org.uk/information

Gingerbread – publish '***The Lone Parents Guide to Caring for a Child with Additional Needs***'. One copy free to each lone parent. Telephone advice service Mon-Fri 9-5pm **Freephone Tel: 0808 802 0925** www.gingerbread.org.uk

Changing Faces – provides information, individual help & emotional support to those affected by facial disfigurement **Tel: 0845 450 0275**
www.changingfaces.org.uk

Carers Christian Fellowship – offers regular newsletters and links to other carers, occasional fellowship days arranged **Tel: 01793 887068**

The Challenging Behaviour Foundation – information and support for parents and carers of people with severe learning disabilities with challenging behaviour. Family Support Line **Tel: 0845 602 7885** www.thecbf.org.uk

Well Child – information and support for children and families including practical support to parents of sick children in their own homes. Helpline [local rate] **Tel: 0845 458 8171** www.wellchild.org.uk

Working Families – provides a network, a newsletter and a helpline for parents who work, or want to work and who have children with disabilities. Helpline on Mon/Tue 10-4pm & Thu/Fri 10-1pm.
Freephone Tel: 0800 013 0313 www.workingfamilies.org.uk

If you want to ask for help or a service but cannot quite make the call, then ask a friend to help.

NB: Most conditions will have a national organisation which can provide useful information. If one is not mentioned in this booklet you may easily find out by searching on the internet. **Maidstone Carers Project** can do this for you.
Tel: 01622 685276

14. TAKING A BREAK **[sometimes called respite care]**

CARE AT HOME

Crossroads Care West Kent – may be able to provide you with a regular weekly break of 2-3 hours by providing a trained carers support worker in your home. This is a free service. **Tel: 01622 817114**

Crossroads Young Carers Project – provides support, advice, befriending for young carers. Also an evening break in a local youth club, trips and holidays, so that they can relax and have fun with others in similar situations. Contact Jan **Tel: 01622 817114**

DAY CARE

This includes nurseries, playgroups and nurseries for pre-school children

The Childcare Information Service – holds information about pre-school facilities, out of school clubs, play schemes, child minders and day nurseries
Tel: 080 0032 3230

RESIDENTIAL BREAKS

Social Services have five different respite care facilities which take children, from Maidstone & Malling, with learning difficulties aged 8 to 18 years. The timing of breaks is flexible depending on the assessed need of the child and family. Social Services may be able to arrange short breaks elsewhere for children who have a physical disability. Contact your social worker or the Disabled Children Services Team Maidstone **Tel: 01622 746505** / Malling **Tel: 01732 362442 or 0845 330 2967**

Aiming High – Government transformation programme for disabled children's services. For local information on short breaks contact Kent Contact & Assessment Service **Tel: 08458 247100**

Demelza Hospice Care for Children – may be able to provide residential respite and palliative care if your child has a life limiting condition. Ring their Care Team to discuss. **Tel: 01795 845200** www.demelza.org.uk

Harvest Trust Holidays for Children – provides free week-long seaside holidays for groups of up to twelve disadvantaged children at the Trust's own holiday centre in West Wales. The holidays are organised in partnership with schools, community groups and child care organizations **Tel: 01559 371190**
www.harvesttrust.com

National Autistic Society [NAS] Radlett Lodge School, Radlett, Hertfordshire – provides a respite service at weekends and during school holidays for families across the London Boroughs and surrounding counties. Call Tamsin Adams **Tel: 01923 854 922**

Kent & Medway Social Care Partnership Trust – run a bungalow in Court Drive which provides short term respite care for children and young people with severe learning difficulties. Contact the Residential Services Manager **Tel: 01622 776300.**

Kent Kids Miles of Smiles – Footprints is a care home with 6 permanent places and 6 respite care beds for sick and disabled children between 3 & 18 years of age inclusive. Parents can access this service directly - donations requested **Tel: 01227 780796** www.miles-of-smiles.org.uk

Kiloran trust – is a registered charity providing residential supportive 5 night breaks for carers in their West London House. For those on means-tested benefits Kiloran will try to get the cost of stay covered **Tel: 0207 602 7404**
www.kilorantrust.org.uk

Link Scheme – respite care is given free by Link Carers [trained volunteers] looking after special needs children for a few hours or a whole day on a regular basis to give you a break. [There may be a wait while finding a Link Carer]. **Tel: 0845 330 2968**

Margaret Champney Rest & Holiday Fund – offers one-off grants to carers who need a complete break away from their caring role or a recuperative holiday. Applications from Social Worker or Carers Worker **Tel: 01394 388746**
www.theogilvietrust.org.uk

15. SOCIAL SERVICES

YOUR NEEDS

Carers have a right to an assessment of their own needs under the **Carers [Recognition & Services] Act 1995** and the **Carers & Disabled Children Act 2000**. Parent carers are included in the provision of these Acts. However parents of disabled children will usually receive an assessment and services for their family under the provisions of the **Children Act 1989**. It is recognised that

providing services which support parents will often be the most effective way of promoting the welfare of the child.

WHAT TO DO

Be sure to tell the Social Worker what you need and what would make life easier for you, eg changes to the home and equipment to help you, an occasional or regular break, to be in touch with other parents etc. These needs will then be taken into account when deciding what services will be offered.

Disabled Children Services Team Tel: 0845 824 7100

16. MONEY FOR YOU

Carers Allowance – the main benefit for children with disabilities is **Disability Living Allowance [DLA]**.

There are two parts:

- one for care
- one for mobility

If your child gets the care part at the middle or higher rate, you as the carer may be entitled to **Carers Allowance [CA]** for looking after your child. For further information contact the **Freephone Benefit Enquiry Line**
Tel: 0800 882200.

Carers Premium – if you are eligible for Carers Allowance but already receive Income Support, the amount of income support you get will be reduced by the amount of CA you receive. However, it is still worth applying as you will then be entitled to an additional amount of income support called a **Carers Premium**.

The Carers Premium can also be paid if you receive Housing Benefit, Council Tax Benefit and Job Seekers Allowance. For further information see telephone number above.

Carers Credit – if you are of working age you can apply for a weekly Carer's Credit to protect your State Pension. You only need to be caring for 20 hours per week or more [including combined hours if you care for more than one person]. Tel: **0845 608 4321**

Carers UK – this organisation provides helpful free booklets called '**Benefits for Carers**' and '**Carers Allowance**' and '**Carer Premium**'.

Tel: 0808 808 7777 www.carersuk.org

If you require further information contact:

Maidstone Carers Project Tel: 01622 685276

www.vam-online.org.uk/carersproject.asp

Detailed information about all aspects of caring for a child with special needs can be found in '***The Maidstone Resource Directory***' on the **Bower Grove Parent Support Group** website **www.bower-grove.kent.sch.uk/parents-support**

Useful websites

www.nhs.uk/carersdirect

www.digitalmaidstone.co.uk (Maidstone Borough Council)

www.tmbc.gov.uk (Tonbridge & Malling Borough Council)

www.seap.org.uk/ICAS (Independent Complaints Advocacy Service)

www.vam-online.org.uk/carersproject.asp (Maidstone Carers Project)

www.kentcarersemergencycard.org.uk

www.carersuk.org

www.kent.gov.uk/carers

www.kentppn.com (Partnership with Parents)

www.ace-ed.org.uk (Advisory Centre for Education)

www.kentrustweb.org.uk (Common Assessment Framework)

www.dcsf.gov.uk (Department for Children, Schools & Families)

www.ipsea.org.uk (Independent Panel for Special Education Advice)

www.teachernet.gov.uk (special education needs)

www.childcarefinder.direct.gov.uk

www.slideawayone@aol.com (bereavement support for young people)

www.ndcs.org.uk (National Deaf Children's Society)

www.youngminds.org.uk (Mental Health)

www.workingfamilies.org.uk

www.cafamily.org.uk (Contact a Family)

www.fhaonline.org.uk (Family Holiday Association)

www.mencap.org.uk

www.cerebra.org.uk (Brain Injured Children)

www.connexions-direct.com (Information for young people)

www.gingerbread.org.uk (one parent families)

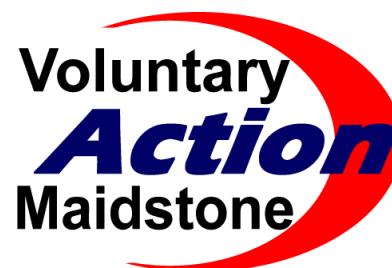
www.4children.org.uk

www.dandeliontime.org.uk

Other leaflets in this series:

- Information for people caring for a friend or relative who is **over 65**
- Information for people caring for a friend or relative who is **under 65 and has an illness, physical disabilities or a sensory impairment**
- Information for people caring for a friend or relative who has **learning disabilities**
- Information for people caring for a friend or relative who **has a mental health problem**

Maidstone Carers Project
Maidstone Community Support Centre
39-48 Marsham Street
Maidstone Kent ME14 1HH
Tel: 01622 685276
e-mail: carers@vam-online.org.uk
www.vam-online.org.uk/carersproject.asp



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