

# Do you look after someone?



# **Carer Information**

This booklet is available on the South Eastern HSC Trust website at www.setrust.hscni.net

# **Trust area with Towns**



# **F**oreword

This booklet has been produced by the South Eastern HSC Trust Carer Support Service. The above map shows the geographic area covered by the Trust. Our role is to develop supports which help carers and we work through professionals on the ground who are in direct contact with families. We also link in with a wide range of carer groups and organisations in the voluntary and community sectors.

This booklet has been compiled to provide a range of information about services provided to carers by the South Eastern HSC Trust; as well as other statutory and voluntary agencies. The work to support carers has been developing over a number of years and carers are encouraged to participate in decision-making about service development.

We hope this booklet will be useful to carers in knowing where to access the help and support that is available.

Carer Support Service South Eastern HSC Trust

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# CONSENT FOR NAME TO BE ON CARER LIST

South Eastern Health & Social Care Trust wants to improve services to people who look after friends or relatives on a regular basis. We are inviting these carers to let us know if they wish their name to be held on a list held by the Trust. This list will be used for the purpose of contacting carers about services, information, support, carer events, etc. If you wish your name to be included on the carers list, please complete your details below:

Carers Name (Print)	Date of Birth	
Carers Address	·····	
	Postcode	
Telephone Email		
Please indicate which <b>Ethnic Group</b> you concluded Chinese, Irish Traveller, Mixed) Please indicate your <b>Nationality</b> (eg Latvia Preferred <b>Language</b>	an, Lithuanian, Polish)	
GP Name and Address		
<b>N.B.</b> You do not have to sign for both organisation the Trust or your doctor to have this information,		
1) I agree to my details as a carer being held by	South Eastern HSC Trust.	
Signature	Date	
2) I agree to my details as a carer being held by	my <b>doctor</b> .	
Signature	Date	
The person I care for is aged: 17yrs or under	18-64yrs □ 65yrs or over □	
Their main illness or difficulty is: Physical <b>L</b> Sight/Hearing <b>I</b>	Learning □ ■ Mental Illness □	
They live in/near:		
	Ballynahinch Downpatrick D  Newcastle Newtownards D  Portavogie D Other	

It is a requirement that any personal information we hold is accurate and up to date. We are therefore depending on you to let us know of any changes to the information provided. If at any time you do not wish us to continue to hold your details please let us know.

Completed forms should be returned to: Carer Support Service, South Eastern Trust, Ballynahinch CommunityServices, 45-47 Main Street, Ballynahinch, BT24 8DN or emailed to carer.support@setrust.hscni.net

July 2018

# **South Eastern HSC Trust Offices**

This is a list of offices in the Trust which provide services to Carers and the people they care for.

# If you are caring for an older person

<b>Down Lisburn</b>		North Down & Ards	
Ballynahinch	(028) 9756 5456	Bangor	(028) 9146 8521
Downpatrick	(028) 4461 3811	Comber	(028) 9187 2779
Dunmurry	(028) 9060 2705	Donaghadee/Peninsula	(028) 9188 3775
Hillsborough	(028) 9268 3609	Holywood	(028) 9044 0443
Lisburn	(028) 9250 1325	Newtownards	(028) 9180 1234
Newcastle	(028) 4372 3346		

# If you are caring for a child/young person with a disability

New Referral: Phone Gateway Team 0300 1000 300

# **Children's Disability Teams:**

Down (028) 4461 3938 Lisburn (028) 9260 7528 North Down & Ards (028) 9147 9688

# If you are caring for an adult with a learning disability

Down (028) 4461 6915 Lisburn (028) 9263 3190 North Down & Ards (028) 9151 1190

## If you are caring for an adult with a physical disability

Down (028) 4461 6915 Lisburn (028) 9260 4031 North Down & Ards (028) 9151 1190

# If you are caring for someone with sensory difficulties

 Lisburn
 Tel:
 (028) 9260 7746
 North Down & Ards
 Tel:
 (028) 9151 0136

 Text:
 (028) 9262 8646
 Fax:
 (028) 9151 0145

 Mobile:
 07739 879 554
 Minicom:
 (028) 9151 0137

 Down
 Tel:
 (028) 4461 6915
 Mobile:
 07525 899 178

Text: **(028) 4461 4744** Mobile: **07739 879 556** 

## If you are caring for someone with mental health difficulties

Lisburn (028) 9266 5181 North Down (028) 9151 1199 Downpatrick (028) 4461 3311 Ards (028) 9151 2156

## If you are caring for someone with brain injury

Down & Lisburn areas (028) 9263 3189 North Down & Ards areas (028) 9151 1192

# Planning Support for You as a Carer

# **Our Aim**

South Eastern HSC Trust aims to recognise and value the work of carers. We will provide a separate assessment/discussion of your needs to support you in your caring role.

# Who is entitled:

A carer is someone who regularly provides a substantial amount of care to a family member, friend or neighbour who is ill, disabled or is an older person.

#### You could be:

- A young person under 18 looking after a parent/brother/sister
- Looking after a relative with a disability
- The parent of a child with special needs
- A friend or relative looking after an older person.

#### You do **not** have to be:

Living with the person you care for **NOR** the only carer **NOR** related to the person you care for. Moreover, you can also get an assessment of your support needs if you are planning to care for someone in the near future, for example, if a relative is due to come home from hospital.

# **The Assessment**

The carer assessment focuses on you as a carer. The purpose is to:

- Support your role and recognise the input you have into the life of the person you care for
- Explore the amount of help or care given and look at the impact of this on you and the life of your family
- Find out your support needs as a carer
- See if your support needs can be met by social services or others.

Account will be taken of a carer's circumstances, views, age, general health and wellbeing and other available supports.

The carer assessment/conversation provides an opportunity to find out what help might be available to support you in your caring role.

## The support might include:

- Information for you as a carer
- Training to help you in your caring role
- Emotional support through support groups, alternative therapies, etc.
- Practical support in the home
- Breaks from caring
- Financial support towards short break, pampering, leisure activity etc.

# **How to get a Support Needs Assessment/Conversation**

Carers have the legal right to an assessment of their own needs, separate from the person they care for.

You can ask for this assessment/conversation when your local care manager, social worker, nurse, etc. assesses the needs of the person you look after. You can discuss your own needs even if the person you look after does not get any services.

Perhaps the person you care for has already been assessed and is receiving services. If circumstances change, for example his/her condition has got worse or you are finding it difficult to cope, you can ask for both your situations to be reviewed by social services.

Carers can telephone the appropriate Trust office listed on page 3 of this booklet or may ask their GP to do this on their behalf. Alternatively, you (or someone on your behalf) can complete the carer assessment referral form on page 23 of this booklet.

# Short breaks from caring

Caring is rewarding but it can also be demanding so it is important that as a carer you get a break from caring to promote your own health and wellbeing. Every carer's needs are different, as are the needs of the people you care for. There are many ways to get a short break from caring and the length of break can range from a few hours weekly; a day here and there; a complete break away for a number of days; or a mixture of these. Trust staff can advise you of the range of ways you can get a short break. More information can be found in the Carers Northern Ireland Factsheet entitled 'Taking a break' at www.carersuk.org/files/section/5042/factsheet-ni1016-taking-a-break-northern-ireland.pdf

# Self Directed Support

The Trust in partnership with the Health and Social Care Board (www.hscboard.hscni.net/SDS) has a way of delivering Social Care Services called Self Directed Support.

**Self-Directed Support** provides much more choice and flexibility to individuals and families allowing them to tailor a package that best suits their lifestyle. This allows the individual or the family to live their lives in the way they want to.

## **How do I get Self Directed Support?**

Self-Directed Support is available to those who have been assessed as being in need of social care support.

If you do not already receive social care support you will need to ask for an assessment from a social worker or keyworker to ensure that you are eligible.

Following the assessment, a personal budget will be agreed to meet these support needs, you can then decide how you want to direct your support using the options available.

Speak to your key worker or the relevant local team listed on page 3. Alternatively, contact the Centre for Independent Living on (028) 9064 8546 or on the internet www.cilbelfast.org

# **Benefits for Carers**

The benefit system is complex and finding out what help is available is not always easy. This section gives a brief overview of benefits for carers. You can get further help and advice from Citizen's Advice Bureau, an Independent Advice Centre, a Disability Organisation or Carers Northern Ireland Tel: (028) 9043 9843. Details can also be found on the internet at: www.carersuk.org/help-and-advice/financial-support

Benefit information was updated in April 2018. Benefits usually are subject to increase in April each year.

# Carer's Allowance

Carer's Allowance is the main benefit for carers. It is paid at a basic rate of £64.60 a week

You can get Carer's Allowance if:

- For at least 35 hours a week, you look after someone who gets Attendance Allowance or the daily living component of Personal Independence Payment at either rate or Constant Attendance Allowance (of the normal maximum rate) paid with the Industrial Injuries or War Pensions Schemes and
- You are over 16 and
- You are not in full time education. The meaning of 'full time' is complicated and may depend on a number of factors so seek advice if unsure and
- You earn £120 a week or less (after specified deductions); you should seek advice if not sure and
- You do not receive one of a list of other benefits paid at a higher rate than Carer's Allowance and
- You satisfy UK presence and residence conditions.

Sometimes, if you are paid Carer's Allowance, the person you care for may lose some of their benefit. If you are unsure seek further advice from Carer's Northern Ireland on (028) 9043 9843 or email: advice@carersni.org

# **Means-tested Benefits**

If you are paid Carer's Allowance, it will count as income when your means-tested benefits are calculated. However your means-tested benefit calculations will include a carer premium, carer addition or carer element. The **carer premium** is an extra amount of money included in the calculation of Income Support, income-based Jobseeker's Allowance, income-related Employment and Support Allowance, Housing Benefit, and Rate Relief. The **carer addition** is an equivalent amount paid with Pension Credit. The **carer element** is an equivalent amount paid with Universal Credit.

What this means in practice is that if you are paid Carer's Allowance and are already getting a means-tested benefit, your means-tested benefit will decrease slightly, but overall you are likely to be better off by the amount of the carer premium, carer addition or carer element.

# Employment & Support Allowance (ESA)

You receive a National Insurance Contribution Credit for each week that you qualify for Carer's Allowance. The credit protects your State Retirement Pension. Carers caring for a total of 20 hours per week or more will be able to apply for Carers Credit to protect their state pension. For more information contact Disability and Carers Service on **0800 587 0912**.

# **National Insurance Credits**

ESA is a benefit for people whose ability to work is limited by ill-health or disability. Carers may be eligible if they have their own health problems as well as care responsibilities. ESA can either be means tested or based on National Insurance contributions from a previous job. For further information contact Carer's Northern Ireland on (028) 9043 9843.

# Benefits - People who are ill or have a disability

# Personal Independence Payment (PIP) and Attendance Allowance (AA)

PIPs/DLA and AA are state benefits that help with the extra costs of long-term illness or disability. They are paid whatever your income or savings. They are not taxable. They are paid to the person who has the illness or disability or to the adult responsible for a child under 16. PIP is for people who first claim before the age of 65. AA is for people who claim on or after their 65th birthday.

To claim, call 0800 220 674.

# Financial support and benefit for people on low income

Universal Credit (UC) is a means-tested benefit that is being gradually introduced. It is replacing Income Support, income-based Jobseekers Allowance (JSA), income-related Employment and Support Allowance (ESA), Housing Benefit, Child Tax Credit and Working Tax Credit. These are called 'legacy benefits'.

When UC will affect you will depend on your circumstances and where you live. It is being rolled out gradually and is expected to cover the whole of Northern Ireland by the end of 2018. However if you already receive a legacy benefit and your circumstances don't change, you can expect to move to UC by March 2022.

For more information about UC, contact the Welfare Changes Helpline 0808 802 0020.

# Income Support (IS)

This is for people whose income is below minimum levels set by the Government. It is for people aged between 16 and state pension credit age who do not have to sign-on to claim Jobseeker's Allowance. The minimum level varies with your circumstances. You cannot claim Income Support if you have more than £16,000 in savings.

# **Pension Credit**

Pension Credit is a benefit for people who have reached state pension credit age. The credit has two parts: **Guaranteed Credit** can be claimed by people over the 'qualifying age'. If you are under the 'qualifying age', but your partner can claim it for both of you and **savings credit** rewards people who have a second pension or modest savings. It is paid to you if you or your partner is 65 or over. Your income and saving will affect the amount or Guarantee or Savings Credit you get. To claim call **0808 100 6165** 

# **Tax Credits**

There are two tax credits - Working Tax Credit and Child Tax Credit.

Working Tax Credit is for people who are in work. The amount you get depends on your income and personal circumstances.

Child Tax Credit is for people with a child under 16 or under 19 if they are in education. You may be able to get extra credit if you have a child with a disability. Tax credits helpline **0345 300 3900**.

# **Rate Relief**

If you have a low income, you may be able to reduce your rates by claiming Rate Relief. For more information about Rate Relief contact your local Housing Executive Office or Land and Property Services.

# Work and caring

It can be difficult to manage work and caring responsibilities. Some carers have to change their work arrangements, need to be contactable by phone, or may need to take leave at short notice for emergencies. Carers now have more statutory rights at work that help to meet these needs. Employers may also be able to offer additional flexibility through their own policies and procedures.

Most carers have the right to request flexible working or to take a 'reasonable' amount of time off (paid or unpaid) to deal with emergencies. The relevant laws are The Work and Families (Northern Ireland) Order 2006 and The Employment Rights (Northern Ireland) Order 1996).

Some carers may feel that the caring is so intensive that they are forced to give up work. It is important to look at all options before making such a decision such as career break, using annual leave, or requesting unpaid leave.

More detailed information is available on the Carers Northern Ireland website at www.carersni.org/information/workandcaring/carersrightsatwork

# **Carers and State Pension**

People often don't think about pension until they come close to retirement age. Caring for someone can have a big impact on your pension longer term and carers need to take extra care of their pensions. State Pensions are made through paying National Insurance contributions. If you are unable to do this because you are caring for a child with a disability or for an adult who is disabled, ill or frail, then the state will credit contributions for you.

Carers caring for a total of 20 hours per week or more will be able to apply for Carer's Credit to protect their State Pension. To claim this you need to be caring for one or more disabled person for a total of 20 hours or more a week where they get Attendance Allowance, Constant Attendance Allowance or the daily living component of Personal Independence Payment at either rate; or Armed Forces Independence Payment; or you will need a medical or care professional to confirm that you are providing appropriate care for them. More detailed information is available at <a href="https://www.carersuk.org/help-and-advice/financial-support">www.carersuk.org/help-and-advice/financial-support</a>

# **Training for carers**

The South Eastern HSC Trust recognises that some carers may need training to enable them to fulfil caring responsibilities without affecting their own health and well being. Staff already provide a range of training as part of their role in supporting carers eg. managing medicines, swallowing, moving and handling. Carers may identify additional training needs to be addressed. A form has been designed to facilitate referral for Carer Training (see page 21) This form can be completed by a carer or someone else on their behalf.

# **Carers & hospital discharge**

If someone you care about has been in hospital and that person will not be able to manage at home without your help, then you are a carer. Perhaps you are bringing a relative home who used to live elsewhere or you are providing additional support for them in their own home. You may be wondering how you will cope with someone whose life has been considerably changed due to injury, illness or frailty impacting on their ability to manage independently. Or, you may have been looking after someone at home until now, but are unsure whether you can continue provide all the help they may need after their hospital stay. It is important for staff to ensure that you, the carer, are involved in decisions about the patient during their stay in hospital and when they are being discharged. The Hospital Social Worker should be able to help. In the South Eastern HSC Trust Hospital Social Workers are based in the Downe Hospital (028) 4461 3311, Lagan Valley Hospital (028) 9266 5141 and the Ulster Hospital (028) 9048 4511. It may be appropriate to consider asking for an assessment of your support needs as a carer. (See page 4 for more information).

# Who to contact if an emergency arises?

# **During Office Hours (9.00am - 5.00pm)**

For medical emergencies contact the GP.

For **social care emergencies** contact the relevant professional who is in contact with the person you care for. If the person you care for does not have any professional involved, please contact one of the offices listed on page 3.

# **Outside Office Hours (Evenings and Weekends)**

For **medical emergencies** contact the Out of Hours GP service as follows:

Down and Lisburn (028) 9260 2204 North Down and Ards (028) 9182 2344

For social care emergencies contact the Emergency Duty Team: (028) 9504 9999.

## **Blue Badge - Parking for Disabled People**

The Blue Badge parking scheme in Northern Ireland for people with certain disabilities allows on-street parking close to facilities and services to improve lifestyle, independence and freedom of choice. Further information and an application form can be obtained by phoning (028) 6634 3700 or on the internet at <a href="https://www.roadsni.gov.uk/index/bluebadge.htm">www.roadsni.gov.uk/index/bluebadge.htm</a>

## **Public Accessible Toilets**

Keys are available for disabled people to access public toilets. The National Key Scheme (NKS) offers independent access to disabled people to around 7,000 locked public toilets around the UK and N Ireland. Keys can be obtained from local council facilities. A more detailed guide is available on the Internet at **radar-shop.org.uk/** where keys can also be purchased.

# **Useful contacts for carers**

This is a list of some organisations who offer information to carers. Some offer general advice and others offer advice to carers of people with a specific illness, frailty or disability.

#### **Carers Northern Ireland**

They provide information and advice for carers on a range of topics relating to caring. They are part of Carers UK and campaign on behalf of carers on policy matters.

Tel: **(028) 9043 9843** Email: **advice@carersni.org** Contact person: Lesley Johnston Carers Line: **0808 808 7777** on Wednesdays and Thursdays from 10.00am - 4.00pm.

## Age NI

They provide information and support for older people (60+) and their carers.

Tel: (028) 9024 5729 Advice line: 0808 807 575 Email: info@ageni.org

Website: www.ageni.org

#### Alzheimer's Society

The Society provides information, advice and support for people with all forms of dementia and their carers. There are carer support groups running in some areas.

Helpline: **03002 221 122** Email: **nir@alzheimers.org.uk www.alzheimers.org.uk** To access independent information, support and services contact your local office.

North Down & Ards (028) 9181 0083 Down & Lisburn (028) 9756 4681

northdownandards@alzheimers.org.uk downandlisburn@alzheimers.org.uk

Dementia Helpline 0300 222 11 22

#### **AutismNI**

Provide information to people with autism, their families and carers...

Tel: (028) 9040 1729 Email: info@autismni.org www.autismni.org

Parents/Carers can ring the offices of Autism NI for details of current groups.

#### **Aware**

Provides information and advice for people who have depression, their families and carers and run education programmes. They also arrange public talks on depression and related topics.

Tel: (028) 9035 7820 Email: info@aware-ni.org www.aware-ni.org.uk

## **Brain Injury Matters NI**

Provides information and support to people who have had an acquired brain injury, as well as carers and families. Also offers free specialist counselling service and training for families.

Tel: (028) 9070 5125 Email: info@braininjurymatters.org.uk www.braininjurymatters.org.uk

## **CAUSE**

Provides practical and emotional peer support to families and friends of people with mental health difficulties. There are a number of local Carer Advocates who run support groups, education and training programmes, a 'listening ear' and carer representation.

**Down Lisburn area** - Brenda McFall Tel: (028) 9062 2008 or 07966 809 427

Email: brenda@cause.org.uk Helpline: 0845 6030 291

North Down & Ards area - Edwina Agahi Email: edwina@cause.org.uk Tel: 07921 373 569

#### **Contact Northern Ireland**

Provides information and advice to families who care for children with a disability or special needs.

Tel: (028) 9262 7552 Email: lindsay.wallace@contact.org.uk

www.contact.org.uk/northernireland

## **Down's Syndrome Association**

Provides information on Down's Syndrome. Information packs on Down's Syndrome and dementia can be provided.

Tel: (028) 9066 5260 Email: enquiriesni@downs-syndrome.org.uk www.downs-syndrome.org.uk

#### Lifeline 0808 808 800

Calls to Lifeline are answered by qualified counsellors who can provide immediate help and support. Lines are open 24 hours a day, every day of the year. Calls are free from all landlines and mobiles.

## **Macmillan Cancer Information & Support Service**

Provides a range of information and support to all those affected by cancer, including family and friends. This service is available for those who have been affected by cancer in any way from those with concerns relating to diagnosis to those who wish to know how to reduce their risk. It provides a 'one stop shop' for all services relating to cancer in the South Eastern HSC Trust area.

Tel: (028) 9055 3246 Email: macmillan.informationandsupport@setrust.hscni.net

#### Mencap

Provides information, residential, education and employment services, leisure opportunities, individual support and advice for people with a learning disability, their families and other carers. Freephone Helpline: **0808 808 1111** Email: helpline.ni@mencap.org.uk www.mencap.org.uk

## **Mindwise**

Provides information and advice for those with severe mental illness, their family and carers. They also provide community services including volunteering opportunities, supported housing, day services.

Helpline: **(028) 9040 2323** Telephone: **(028) 4461 7964** for information about current carer groups. Email: **info@mindwisenv.org downpatrick@mindwisenv.org www.mindwisenv.org** 

# **National Autistic Society NI**

Provides a range of supports for families caring for someone with autism.

Tel: (028) 9068 7066 Email: northern.ireland@nas.org.uk www.nas.org.uk

## **Neurodiversity UK**

Neurodiversity UK aims to help and support both children and adults affected by learning difficulties, mental health conditions and neurodevelopmental disorders through advice, education and sport.

Tel: (028) 9122 5704 Email: comberasg@outlook.com

## NI Chest, Heart and Stroke

Provides advice for people who have had chest or heart problems or who have had a stroke; as well as their carers.

Helpline: (028) 9040 2323 Email: mail@nichs.org.uk www.nichs.org.uk

#### Parkinson's UK

Provides information and support for people with Parkinson's Disease and their families and carers.

Head Office: (028) 9092 3370 www.parkinson.org.uk

Tel: 0844 225 3794 Email: northernireland@parkinsons.org.uk

#### The Stroke Association

Provides information and advice to adults who have speech difficulties, their families and carers.

Tel: 0303 3033 100 Email: info@stroke.org.uk www.stroke.org.uk

From a textphone: 18001 0303 3033 100

# **Additional useful websites**

These websites may provide additional useful information for carers. South Eastern Trust cannot take responsibility for the content of these websites nor the accuracy of information contained in them.

South Eastern Health and Social Care Trust setrust.hscni.net

NI Direct official government website with information for carers www.nidirect.gov.uk/index/caring-for-someone.htm

Rural Transport Information www.imtac.org.uk

NI Human Rights Commission website www.nihrc.org

Family Fund supporting families with a child with disability aged 17 and under www.familyfund,org.uk

Stress self help guide www.setrust.hscni.net/pdf/dtress.pdf

# **Local Carer Support Groups**

This is a list of carer support groups running in South Eastern HSC Trust. It is best to check with the named contact that the meeting times are as outlined and that the group isn't on an outing or social event outside the usual meeting place.

# **General Carers Support Groups** which offer support to all carers.

# **Ards Carers Group**

Meet fortnightly Thursdays 10.00am - 12.00pm in St Mark's Church, Church St, Newtownards

## **Colin Carers Group**

Meets in Cloona House 1st Monday of each month 11.00am - 1.00pm. Contact Isobel Flood on **07592 748 129** 

# **Killinchy & District Community Carers Association**

The meetings are held at Lisbane Community Centre.

Contact: Lynne McKenzie on (028) 9754 2739 or Hazel Gilles on (028) 9754 2335

## **Lisburn Group**

The meetings are held in the Lisburn area on last Wednesday of month 7.30pm - 9.30pm Contact Anita McKillion on (028) 9267 7233

## West Church Carers Group, Bangor

Meet on the 1st Tuesday of each month 7.30pm - 8.30pm. Contact Margaret Webb on **(028) 9146 1883** 

# **Groups for Carers of people with Dementia**

#### **Alzheimer's Society**

Alzheimer's Society run a number of carer groups; and activity groups for people with dementia and their carers. For further details phone **0300 222 11 22** or local dementia support worker below:

#### **Down & Lisburn Areas**

Tel: (028) 9756 4681 Mobile: 07918 706 106

Market House, 16 The Square, Ballynahinch BT24 8AE

#### **North Down & Ards**

Lynda Williams Tel: (028) 9181 0083

Unit A4, Strangford Business Park, Jubilee Road, Newtownards, BT23 4YH

# **Lisburn Dementia Carers Support Group**

River House, Lagan Valley Hospital 7.30pm - 8.30pm 1st Thursday of every month excluding January, July, August.

Barbara Canning, Dementia Navigator, Level 6 Lisburn Health Centre Tel: (028) 9266 5181

# **Groups for Carers of people with Autism**

# **National Autistic Society**

Group for parents caring for an adult with autism. They provide support to children, parents and family affected by the Autism Spectrum Disorder.

Email: northern.ireland@nas.org.uk Tel: (028) 9068 7066 www.autism.org.uk

# Ards group for Parents and Carers of children with autism

Rosemary Cunningham **07766 874 172** 

#### **AUTISM NI**

Groups for carers of people with autism (028) 9040 1729 For details of groups please ring Head office AutismNI

# **CAPAA: (Children, Adults, Parents And Autism)**

Provides support for adults and parents and young children with Autism Spectrum Disorder. For details please contact Moira Denvir Tel: **07999 525 323** 

# Other Carer Support Groups

# Age North Down & Ards Group

Various groups for people aged 50 years and over.

They meets at Age NDA premises, 24 Hamilton Road, Bangor. For details Tel: **(028) 9127 1968** Email: agenda@agenorthdownards.co.uk

# **Brain Injury Carers Groups**

Lisburn Support group for clients with acquired brain injury, family members and carers.

Meet at Thompson House Hospital, Lisburn 3rd Thursday of each month.

Contact Brydee Ross for further details Tel: (028) 9263 3189

Group in the North Down & Ards area are run in different location depending on group membership. Contact Brain Injury Team for details Tel: (028) 9151 1192

# **Carers Forum on Learning Disability**

Provides support and advice through an advocacy service for carers of people with learning disabilities. Lobbies statutory bodies to improve standards and services. Forum works in partnership with South Eastern HSC Trust.

Meet 1st Wednesday monthly 7.30pm - 9.15pm Lisburn Oakmont House, Queens Road Lisburn. Anne Blake Tel: (028) 9266 2690 OR Forum Mobile 07973 726 505

#### **CAUSE**

Support for carers of people with mental health difficulties are held monthly in Ards and Lisburn Areas.

Down Lisburn area - Brenda McFall Tel: (028) 9062 2008 or 07966 809 427

Email: brenda@cause.org.uk\_ Helpline: 0845 6030 291

North Down & Ards area - Edwina Agahi Email: edwina@cause.org.uk

Tel: **07921 373 569** 

There are monthly support groups held in both the Ards and Lisburn areas. Please contact Carer Advocates for further details.

## **Lisburn Downs Syndrome Support Group**

Carers of people with Downs Syndrome. Meet once a month location varies.

Rosemary Gorman Tel: (028) 9266 9742

## **Lisburn Downtown Centre Contact Group**

Carers of children and adults with learning difficulties.

Meet 2nd and 4th Tuesday monthly Downtown Centre, 49 Market Square South, Lisburn.

Centre Coordinator Tel: (028) 9267 2052 Email: info@downtown.centre.org

www.downtowncentre.org

# **MUMS (Mothers Understanding Mothers Support)**

For mothers who have children with learning difficulties/special needs meet 1st Thursday monthly 7.30pm - 9.30pm in various locations in Downpatrick.

The group meet monthly in the Sure Start Building, 31 Mount Crescent, Downpatrick

Marie Claire Bradley Tel: 07921 809 118

## Mindwise Down Area

Carers of people with mental health difficulties. Range of carer support sessions offered. One to one support offered on appointment. For details contact Jim Darragh Tel: (028) 4461 7964

#### **NI Chest Heart & Stroke**

Carers of anyone who has had a stroke.

#### Down & Lisburn Area

Stroke Family Liaison, Isobel Hyde Tel: 07764 211 535 Email: ihyde@nichs.com

#### North Down & Ards Areas

Stroke Family Liaison Maureen Boyle Tel: 07714 844 210 Email: mboyle@nichs.com

## North Down & Ards Down Syndrome Assocation

Parent led group for families of people with Down's Syndrome in the Bangor, Ards, Holywood and Ards peninsula areas. They provide a range of activities and they meet bi-monthly on 3rd Tuesday of the month 8.00pm in the George Green Community Centre in Bangor.

Contact Lorraine Brown on 07754 431 234 or Nicole Stewart on 07730 430 988

# Parkinson's Carers Groups

For Carers of people with Parkinson's disease.

#### Lisburn

Meet 3rd Monday monthly 2.30pm - 4.30pm in Conference Room, Graham Gardens, Lisburn Paula Mc Larnon Tel: **03442 253 684** 

#### **North Down & Ards**

Meet 3rd Monday monthly 2.00pm - 3.30pm in Town Hall Arts Centre, Newtownards.

Paula Mc Larnon Tel: 03442 253 684

# Carers from Black & Minority Ethnic Backgrounds

South Eastern HSC Trust is committed to ensuring equality of access to services and information to all people who look after someone living within its area.

The Trust provides services to a diverse and multi-cultural community and is asking carers about their ethnic group so that we can meet their cultural, religious and language needs better. If you would like to be included in the Trust carer list please complete the consent form on page 2 and if you would like to speak to a staff member about your support needs as a carer please complete the form on page 23.

Everyone belongs to an ethnic group. An ethnic group is how you see yourself and is a mixture of culture, religion, skin colour, language and the origin of your family.

## You may be asked:

- What is your Country of birth? eg. Northern Ireland / Poland / Romania
- What is your ethnic group? eg. Chinese / Irish Traveller / Mixed Ethnic Group

No-one has to disclose this information but if you do, it will be treated confidentially and will help us plan our services and provide for your particular needs.

# Why Ethnic Monitoring is needed

Ethnic monitoring by service providers is key in helping to promote racial equality. Developing ethnically sensitive services will meet your needs better.

- It promotes equality and human rights
- It improves access to services
- It helps identify gaps in services
- It promotes more culturally sensitive services
- We want everyone, no matter what their ethnic group to be able to use our services easily
- It will help us to understand your individual needs
- it will help us to respond to your needs to provide better services.

Where asked, this information will be recorded to help us identify groups who are using, or not using, services to help us meet your needs and plan better for future services.

## **Data Protection**

The information collected will be used alongside other carers' information to identify overall needs and to help us plan our service. All personal details will be covered by the Data Protection Act 1998 and kept strictly confidential.

# **Carer health**

A carer's lifestyle is frequently restricted and many carers can, and do, get mentally and physically exhausted by their caring role. This can cause their health to deteriorate, which is why it is important for you to take stock of your own health. Carers need to keep healthy to care.

This questionnaire will help you start thinking about your own health and see how healthy you are. If you have any concerns about any aspect of your health, speak to your GP or Practice Nurse. You should have regular medical checks with your GP.

How often do you have your health checked?		Health tips
NEVER	1	A health check involves checking: Blood pressure; weight; urine as well as a general
OCCASIONALLY	2	discussion about your health.
REGULARLY (every 1 to 3 years)	3	
How are you feeling?		
TIRED MOST OF THE TIME	1	Need advice? Talk to your GP or Practice Nurse.
TIRED OCCASIONALLY	2	
RARELY TIRED	3	
Are you physically active for 15 minutes or more each day? (Walking briskly, cycling, swimming, keep fit etc.)		
RARELY OR NEVER	1	Being <b>physically active</b> for half an hour five days a week will keep you active for life. This can be an
ONCE A WEEK	2	enjoyable way to take a break, relieve stress and socialise.
2 OR 3 TIMES A WEEK	3	Socialise.
Do you eat regularly? (breakfast, lunch and evening meal)		
NO	1	<b>Meal times</b> are an opportunity to relax. This aids digestion, helps to reduce tension and increase
SOMETIMES	2	energy.
YES	3	It is important to take meals regularly and remember that breakfast is a good start to the day.
Do you have a balanced diet? (See Health tips for advice)		
NO	1	Your daily diet should include: fruit/vegetables; starchy foods such as breakfast cereals, potatoes,
SOMETIMES	2	bread;
YES	3	Lean meat, fish, eggs and nuts; milk, cheese and yoghurt; butter, margarine and oils (used sparingly).
Do you eat high fibre foods?		
NO	1	High fibre foods (wholemeal bread, brown rice,
YES	3	pasta, peas, beans and lentils, fruit and vegetables and jacket potatoes) can help you relieve constipation, lower cholesterol and control diabetes.
<b>How often do you eat convenience foods?</b> (Takeaways, burgers, chips, crisps, chocolate, cakes and biscuits)		
DAILY	1	
ONCE OR TWICE A WEEK	2	
OCCASIONALLY	3	
How many cups of fluid do you drink each day? (Non-alcoholic, e.g. water, tea, coffee, milk, fruit juice, soft drinks)		
LESS THAN 8	1	Fluid intake is recommended to be 8 to 12 cups per day, which helps to: flush out the kidneys; prevent
8 TO 12	2	urine infections and constipation. You should drink even more in hot weather. Tea and coffee are
12 OR MORE	3	stimulants and may keep you awake if taken before bedtime.

How much alcohol do you drink?		
OVER 14 UNITS A WEEK	1	Alcohol in excess can: affect concentration, memory and reactions; lead to stomach disorders
UNDER 14 UNITS A WEEK	2	and high blood pressure.
OCCASIONALLY/NEVER	3	
Do you smoke?		
YES	1	<b>Smoking</b> increases the risk of: heart disease; lung disease (e.g. bronchitis, cancer)
OCCASIONALLY	2	and osteoporosis (brittle bone disease) Smoking affects other people too (passive smokers). Want to
NO	3	give up? Ask your GP for advice.
How often do you have your sight tested?		
NEVER	1	Eye tests are recommended every two years to help show your general state of health; diagnose
OCCASIONALLY	2	certain medical conditions; and show whether you need glasses. Eye tests are free to some people
REGULARLY (EVERY 2 YEARS)	3	(ask the optician) and some make home visits to the housebound.
How often do you have a dental check up?		
NEVER	1	<b>Dental check ups</b> are recommendedevery 6 months for natural teeth; annually for dentures (well
OCCASIONALLY	2	fitting dentures aid digestion).
REGULARLY (EVERY 2 YEARS)	3	Dentists can give advice and spottooth decay, gum disease and early mouth cancers
How much do you sleep?		
UNDER 4 HOURS	1	<b>Difficulty sleeping?</b> Have you tried relaxing in a warm bath; bedtime
4 TO 6 HOURS	2	snack of milk and fruit; soothing music and light reading.
6 TO 8 HOURS	3	reading.
Do you have time for fun, study, friends and hobbies?		
NO	1	<b>Do you have time</b> for studies, friends and hobbies? How about a relaxing swim, listening to music or
SOMETIMES	2	painting?
YES (DAILY)	3	

# Now find out your score

Add up the numbers in the boxes you have ticked

If your score is....

**30 - 42** Excellent, your lifestyle is healthy. Keep up the good work

**20 - 30** You would benefit from making some small changes to your lifestyle. Have you read the Health Tips?

**14 - 20** Room for some lifestyle changes. Why not have a chat with your GP or Practice Nurse?

# Recognising stress and coping with it

Stress simply means strain or pressure and is brought on by changes in your life. Not all stress is bad. We all need some stress in our lives to function effectively - some people thrive on stress; it makes them feel stimulated and excited. However, constant stress can be destructive and can be likened to an overloaded shopping basket the handles of which weaken and begin to break with the strain. Likewise, a stressed or overloaded carer can become physically or mentally ill.

If you are suffering from stress you are not alone. Most people suffer stress symptoms at some time in their lives. Recognising your stress symptoms is half the battle.

# **Recognising stress**

Carers under stress can experience:

- Anxiety and poor sleep
- Constantly feeling tired
- Difficulty concentrating
- Frustration, feelings of helplessness
- Loss of self-esteem and confidence
- Under- or over-eating, drinking or smoking

- Restlessness feeling guilt when relaxing
- Irritability and aggressiveness
- Tension eg. in neck and back
- Feelings of loneliness and isolation
- Palpitations.

# How to cope with stress?

- Work out what is making you stressed
- Try not to worry about things that you cannot change deal with those that you can change
- Organise your time make lists
- Take regular exercise try a brisk walk
- Avoid harmful ways of coping compulsive eating, drinking or smoking
- Learn to relax, make time for yourself, borrow a relaxation audiotape from your local library.

We all feel stress in our lives.	NO	Sometimes	Yes
Do you feel stressed?	1 □	2 🗆	3 □
If you are stressed, what do you think causes it?			
Unrelated to caring activities	1 □	2 🗆	3 □
Often feeling helpless	1 □	2 🗆	3 □
Not enough hours in the day	1 □	2 🗆	3 □
Feeling lonely – no one to talk to	1 □	2 🗆	3 □
No time to socialize	1 □	2 🗆	3 □
How do you feel about yourself?			
In poor spirits most of the time	1 □	2 🗆	3 □
Lacking in energy	1 □	2 🗆	3 □
That your situation is difficult	1 □	2 🗆	3 □
That you have more problems than most	1 □	2 🗆	3 □
That you have dropped many activities/interests	1 🗆	2 🗆	3 □
You prefer to stay at home rather than go out and do new things	1 🗆	2 🗆	3 □

Now find out your score – add up the numbers in the boxes you have ticked If your score is ......

13 - 20 Good You are keeping your stress under control but remember to make regular time for relaxing activities.

**20 - 30** You would benefit from making some small changes to your lifestyle. Try the 'How to Cope with Stress' tips above. Make regular time for yourself to enjoy relaxing activities.

**30 - 36** You need to relax more. Try the 'How to Cope with Stress' tips above. Have a chat with your GP or Practice Nurse.

# Young carers

Young carers have not been recognised for the role they provide within the family and it is difficult to measure the actual contribution they make. Their caring activities are uncosted and should not be viewed as an appropriate mechanism for the delivery of care in the community.

To respond to the needs of young carers there is a requirement not only to understand the demands of the caring role but also the direct impact it can have on the lives of those involved. The weight of caring responsibilities can prove to be so great that there is little opportunity to socialise with friends or join after-school clubs and youth groups. Even when this does occur, the young carer can have great difficulty forgetting the demands of caring home life.

Caring by young people can have a major influence on life chances and future expectations. It can affect their self-perception; self esteem and the ability to take up opportunities that are available to their peers. It is therefore paramount that young carers views on their caring role are sought and that their personal needs are assessed separately from the needs of the person they care for.

South Eastern HSC Trust is committed to providing support to people who have substantial care needs to minimise the level of caring required by young carers.

# Supports for Young Carers within South Eastern HSC Trust

South Eastern HSC Trust is committed to providing support to people who have substantial care needs to minimise the level of caring required by young carers. In addition, support is provided to young carers through Action for Children Young Carers Project (028) 9046 0500 which provides a variety of supports to young carers based on their individual needs. These include group activities, 1-1 sessions as well as fun short break activities.

If you are a young carer, or someone who is aware of a young person undertaking a high level of caring, please contact the relevant team listed on page 3 of this booklet to discuss the support needs of the young person and also those of the person with care needs.

South Eastern HSC Trust has a separate information leaflet for young carers which is also available on the Trust website at www.setrust.hscni.net

# **Websites for Young Carers**

Children and Young Person's Commissioner NI www.niccy.org

**Action for Children Young Carers** 

www.actionforchildren.org.uk/in-your-area/services/young-carers/ni-regional-young-carers/

The Children's Society www.childrenssociety.org.uk

Crossroads Caring for Carers Young Carers www.crossroadsyoungcarers.co.uk/

Carer Training Request Form

Carer Support Needs Assessment/Conversation should be offered to the carer prior to completion of this form if one hasn't already been completed.

Carer Details: Name (Print)			D.O.B
Address			
		F	Post Code
Tel No: Home		Mobile _	
The person cared for is a	ged: 17yrs	or under □ 18	– 64 yrs $\square$ 65 yrs or over $\square$
Their main illness or diffi	culty is:	Physical [ Sight/Hearing [	□ Learning □ □ Mental Illness □
They live in/near: Hillsborough □ Holywood □ Newtownards □	Dunmurry Lisburn Comber	□ Newcas	ahinch ☐ Bangor ☐ stle ☐ Downpatrick ☐ nadee ☐ Portavogie ☐ Other
Details of person make Carer □ Please tick and Other □ Please complete Name (Print)	continue to e details be	next section low	/Organisation
Address			
			Postcode
Contact Telephone			
Caring Role: Briefly outline	e the caring <sub>l</sub>	provided	
			4.5.0
Please complete one of the Sole Carer - ie. no help from other sources	Limited Help	- please specify family, friends,	Regular Help - please specify source (eg. care agency family, friends)

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Carer Health:
Physical Health
Emotional Health
Special Requirements eg. Mobility, sight, hearing, language etc
Spoolar Roganomonio og. Mosimiy, olgrit, noarmig, languago oto
Additional Information:
Additional information.
Outline training requested (See checklist on page 3):
1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
Is the carer currently in contact with any staff in South Eastern HSC Trust?
Is the carer currently in contact with any staff in South Eastern HSC Trust?  No □ Yes □ If Yes, which Staff Member and Team
No □ Yes □ If Yes, which Staff Member and Team
No □ Yes □ If Yes, which Staff Member and Team  Is this in relation to: Carer □ Cared for person □ Both □
No □ Yes □ If Yes, which Staff Member and Team
No □ Yes □ If Yes, which Staff Member and Team
No

# Completed forms should be returned to:

Carer Support Service, South Eastern HSC Trust, Ballynahinch Community Services, 45 - 47 Main Street, Ballynahinch BT24 8DN carer.support@setrust.hscni.net

July 2018



# **Carer Assessment Request Form**

A carer is someone who provides substantial and regular care to a family member or friend, who is frail or has an illness or disability.

Carers of any age are entitled to an assessment of their own needs as a carer regardless of whether or not the person they care for is in receipt of services.

A Carers Support Needs Assessment is an opportunity for a carer to talk about the care they provide, how it affects their life and identify the support needed to help them to look after their own health and wellbeing.

Tieaitii aiiu welibeliig	<u>j.</u>	
Carer Details:		
Name (Print)		D.O.B
Address		
		Post Code
Tel No: Home		Mobile
Please indicate w Chinese, Irish Tra		oup you consider you belong to (eg. White,
Please indicate y	our <b>Nationality</b> (	(eg. Latvian, Lithuanian, Polish)
Preferred Langua	age	
The person care	d for is:	
a) Child/Young F	erson	
Name		D.O.B
OR b) Adult aged	18 - 64 years □	65 years or over □
Their main illness	or difficulty is:	Physical □ Learning □ Sight/Hearing □ Mental Illness □
They live in/near:	Hillsborough $\square$	Dunmurry $\square$ Ballynahinch $\square$ Downpatrick $\square$
Bangor □	Holywood $\square$	Lisburn $\square$ Newcastle $\square$ Newtownards $\square$
Comber □	Donaghadee $\square$	Portavogie  Other

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Has the carer had a Carer Support Needs Assessment previously?
YES / NO
If YES, by whom and when approximately
Details of person making Referral:
Carer □ Please sign below:
I provide substantial and regular support to a family member/friend and I would like to have my support needs as a carer assessed.
Carer Signature Date
Other □ Please complete details below
Name (Print)
Role/Organisation
Signature
Telephone
Address

Please return completed form to: Carer Support Service, South Eastern HSC Trust, Ballynahinch Community Services, 45 - 47 Main Street, Ballynahinch, BT24 8DN carer.support@setrust.hscni.net

July 2018

Postcode

# When the caring role changes

Looking after someone can be a huge part of your life and often the demands of caring change over time. It may no longer be possible to look after the person you care for at home. There may come a time when you have to think about life after the death of the person you cared for.

# **Residential or Nursing Care**

As a carer, residential or nursing care for the person you care for is an option you have to consider. It may feel like you are letting the person you care for down, or you are rejecting them, but it is important to remember that you can only do so much as a carer. Caring can be both physically and mentally exhausting and there are often limits to the level of care that can be provided in the home. If the person you care for is no longer able to look after themselves and you are unable to provide the care they need, for whatever reason, residential or nursing care is a sensible and realistic option.

For further information see www.relres.org/index.php

# When the person you cared for has died

Losing someone close to you can be devastating. If you have been caring for that person, the loss can seem even greater. How you cope with the death of the person you cared for is a very individual thing. There is no right or wrong way to feel following a death.

Often people don't know what to say to someone who has been bereaved or are worried they won't say the 'right thing'. Talking to friends and relatives about what has happened, and about the person who died, can help you to come to terms with the death, and to cope with the feelings you have. It can also help to talk to other people who have been bereaved as they should have a better understanding of what you are going through.

For further information see www.cruse.org.uk/ Tel: (028) 9043 4600

# Life after caring

The end of your caring role may take some time to adjust to. Having more time to yourself may give you the opportunity for a much needed rest, but it can also leave you with a lot of time to fill. Some carers find that once they are no longer caring, exhaustion - both physical and emotional - catches up with them and they feel unwell for a while.

It is really important to look after yourself. You may feel isolated after many years of caring and you may feel that this has knocked your confidence. There will come a time when you are ready to think about what to do next. This could be returning to work or education, taking up a new hobby, learning a new skill, or volunteering with a local organisation.

For further information see www.carersni.org/information/whencaringends/lifeaftercaring

# **Comments, Compliments and Complaints**

The South Eastern HSC Trust hopes that the information contained in this booklet will be useful for carers. We want to know how carers feel about the services we provide. Leaflets about Comments, Compliments and Complaints are available from any of the Trusts offices listed on page 3 and should be sent to:

Laura Algie
Complaints/Patient Liaison Manager
Lough House
Ards Hospital
Church Street
Newtownards
BT23 4AS

For further information or to obtain this booklet in another format contact Carers Development Officer (028) 9756 5456