



Respite¹ care is provided on a short term basis for disabled or very ill people who either live at home or attend a respite centre, so that their carers can have a break from care giving. Many of the patients involved might otherwise require permanent placement in a facility outside the home. One of the important purposes of respite is to give family members and carers temporary relief from the stress they experience while providing care for a family member living with a rare disease. Respite care enables the caregivers to maintain the ability to continue care giving. A second purpose of respite is to make it possible for the person living with the disease/disability to live according to their usual daily routine and to provide a place to experience and perform recreational and meaningful activities away from their parents/other caregivers. Respite exists all over Europe under different names and programmes. However many countries are not familiar with the term and as a result services are not available to patients in these countries



Respite Care Services (RCS) can be offered in various ways, these are:

- **Residential respite:** the person living with the rare disease goes away to an adapted centre to be looked after by someone else, a "respite care family", for a while
- **Domiciliary care:** some services offer a caregiver to come to the family's home, and take over care giving duties for a while so that the regular carer can have a break from the daily routine of care giving
- **Day care respite:** day care centre, nursing home, institution or respite care group home with assisted living facilities (no overnight facilities)
- **Emergency respite: services** that gives access to services on short notice in the event of an unexpected emergency occurring.

WHY ARE RCS NEEDED?

The European Commission's Communication on Rare Diseases: Europe's Challenges² documents the need for specialised services for rare disease patients around Europe, including RCSs, to be sustainable in order to pursue their goals. Respite is one of the services most often requested by family caregivers, yet it is in critically short supply, inaccessible, or unaffordable regardless of the age or disability of the individual needing assistance. While the focus has been on making sure families have the option of providing care at home, little attention has been paid to the needs of the family caregivers who make this possible

Without respite, not only can families suffer economically and emotionally, caregivers themselves may face serious health and social risks as a result of stress associated with continuous care giving. Three fifths of family caregivers aged 19-64 surveyed recently by the Commonwealth Fund³ reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non caregivers

WHAT IS THE ADDED VALUE OF RESPITE CARE?

It is the belief of EURORDIS and its European Network⁴ of Respite Care Services that every rare disease patient and carer has a right to respite. It is for this reason that it encourages national patient organisations to request respite at national level and to encourage the government to adopt laws ensuring that the necessary services exist to ensure that patients have a break from the routine of looking after a sick child. The long term implications of providing respite care involve benefits for carers and patients, the former will become better carers because of the breaks respite provides while the latter will see increases in their quality of life and be better looked after as a result.

1 - The term «short break» is used in some countries to describe respite care.
2 - COM (2008) 679 Communication from the Commission to the European Parliament, the Council the Economic and Social Committee and the Committee of the Regions on Rare Diseases: Europe's challenges.
3 - http://en.wikipedia.org/wiki/Commonwealth_Fund
4 - The Respite Care Services Network was created in the context of the European Commission funded, Rare Disease Solidarity Project project which sought to create a European networks for Rare Disease Patient Services.

HOW TO ADDRESS THE ISSUE?

One way of ensuring that respite care is provided in your country is to approach your local public authority and to inform them of the benefits of providing funding for respite services. As well as the significant psychological and medical benefits, they should be made aware of the financial incentives involved in the long term. This type of information is often more effective in convincing decision makers to adjust their budget lines in order to include respite care. This can be done by gathering data at national level regarding the costs of equivalent services in order to show the financial incentive of respite care.

Below is an example of the kind of information that can be collected by each participant in order to show the specific advantages of the service.

Figure 1. Simulation of Respite care savings in France
(Source EURORDIS)

Home care + respite care	Unit cost	Number of days	Total cost
Respite care	500 €	60	30 000 €
Home care ⁵	135 €	305	41 175 €
Tax Credit ⁶	-	-	10 000 €
Financial compensation for 8h/day life auxiliary ^(maximum)	153 €	305	47 000 €
Total cost per person-year	-	-	128 175 €

Institutionalised long term care highly dependent person	Unit cost	Number of days	Total cost
Total cost per person-year	371.55 €	365	135 616 €

The above simulation demonstrates the comparative costs of offering respite versus long term care for patients, it proves in real terms that as well as the significant psychological advantages intrinsic in respite care, there are significant economical incentives. This kind of monetary justification can be very helpful in convincing decision makers of the benefits of investing in this sort of care. In some countries laws already exist which provide for the creation of respite care, such as Sweden⁷, Norway⁸ and the US⁹. It is hoped that these laws will exist in every country one day.

EUROPEAN NETWORK OF RESPITE CARE SERVICES

The network also believes that the rare disease community should be as aware as possible of the services that exist. It is by collecting data regarding the services that exist around Europe that we can ensure that patients across Europe are aware of the services that exist for them today. EURORDIS has created a network in order to build up actions to support its members and to achieve its long term objectives. These consist mainly in best practice recommendations that RCS will benefit from once they become members of the network. The network has collected the advice and experience of its contacts all over Europe so as to develop best practice guidelines. These guidelines are available on the Rapsodyonline.eu and EURORDIS website.

RELATED ISSUES

- Although many general disease respite services may not currently cater for rare disease patients they might have the potential to do so one day. By contacting these existing services, respite providers can be made aware of the respite care needs of RD patients and a respite service for particular diseases can be established.
- RCS creation costs can be reduced by taking advantage of expertise that already exists through the Network of Rare Disease Respite Services.
- The network can help your service to cost your project by supplying RCSs with data regarding the staff/queries ratio and other costs RCSs might have to incur in creating a service.

REFERENCES AND ADDITIONAL INFORMATION

- Best Practices for Rare Disease Respite Care Services <http://www.rapsodyonline.eu/wiki/index.php/BestpracticeRCS>
- Rapsodyonline, list of European Respite Care Services: http://www.rapsodyonline.eu/dev_rapsody/index/listing/base/tRespiteCenter/
- EURORDIS Specific Contribution on Specialised Services for People Living with Rare Diseases to the Public Consultation: «Rare Diseases: Europe's Challenges». <http://www.eurordis.org/IMG/pdf/position-paper-EURORDIS-specialised-servicesFeb08.pdf>
- Norwegian legislation on respite care <http://www.ub.uio.no/ujur/ulovdata/lov-19911213-081-eng.html>
- Swedish legislation on respite care <http://www.socialstyrelsen.se/Sidor/Hem.aspx>
- US legislation on respite care. The Lifespan Respite Care Act of 2006 <http://www.archrespite.org/PublicLaw.pdf>
- Agrenska Centre, Sweden <http://www.agrenska.se/>
- Frambu Centre, Norway <http://www.frambu.no/>
- Hendaye Centre, France http://www.csc.asso.fr/article.php3?id_article=142
- Rehabcare Centre, Ireland <http://www.rehab.ie/care/index.aspx>

5 - Example of a cost calculation (rounded coefficients) of an averagely dependant patient receiving home medical care in the public sector for complex bandages and orthopedic rehabilitation (Karnofsky = 60%) and staying beyond the 30th day in France.

6 - D129-35, 10° du code du travail - dependency allowance Arrêté Préfectoral 11 avril 2007. The specialised housing centre of the Valley of Lunain accommodates handicapped adults who have no more autonomy and whose health condition requires daily and constant care. This establishment ensures accommodation, medical and paramedical care, assistance with everyday life, and maintenance care. Activities and leisure are organised in order to preserve lodger's advantages, prevent a possible regression and moreover to keep the place lively and open to the outside world.

7 - <http://www.socialstyrelsen.se/Sidor/Hem.aspx>

8 - <http://www.ub.uio.no/ujur/ulovdata/lov-19911213-081-eng.html>

9 - 109TH CONGRESS REPORT

2d Session « HOUSE OF REPRESENTATIVES » 1 109-716

LIFESPAN RESPITE CARE ACT OF 2006

DECEMBER 5, 2006.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed