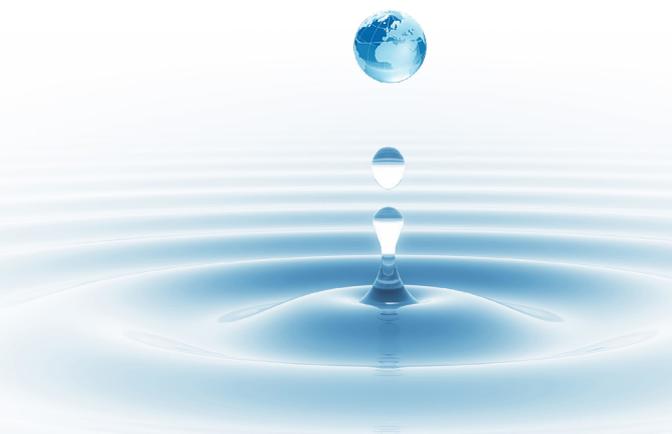


INNOVATIVE CARER PRACTICES

IMPACTING CARERS* AROUND THE WORLD



CAFÉS DES AIDANTS®

Supporting the social and emotional dimensions of caring

Social and emotional well-being are essential to health, wellness and quality of life.¹ Humans have an innate desire to belong, to be engaged and to feel connected to those around us. Taking on a caring role for someone who needs help because of a physical or cognitive condition can have a profound impact on an individual's life course and result in a sense of loss and social isolation.² **This Innovative Carer Practice showcases a national network of 190 Cafés des Aidants® across France, which provide a friendly space for carers to get together, share experiences and access emotional supports.**

CONTEXT

The psychosocial impact of caring is a multifaceted area with perceived satisfaction and discontent varying from one individual to another. Providing unpaid care to a friend or loved-one can make carers feel good about themselves, give meaning to their lives, provide opportunities to learn new skills and strengthen relationships and familial bonds. These rewards often co-exist with negative emotional repercussions such as feeling overwhelmed, increased isolation and loneliness as caring demands limit personal and leisure time. A study of carers conducted by the French Association of Carers³ in 2016 reported that:

- 59 percent feel alone
- 70 percent do not spend time on recreation
- 48 percent believe their health status has worsened because of their caring role

A study across the OECD countries, *The Impact of Caring on Family Carers*,⁴ also indicated that carers, especially those providing a high level of care, experience greater social disadvantages and are more susceptible to mental health problems.

Many carers find themselves taking on one pressing task after another without pausing to consider the impact on

their own health and well-being. Even if they are aware of potential effects, they find it difficult to talk about their feelings or dismiss them because they believe they should be able to cope. Consequently, carers minimize and ignore their social and emotional difficulties due to guilt, fear of being judged or believing no one understands their situation.

To promote carers' health and overall well-being, greater attention must be given to the social and emotional dimensions of caregiving. The French Association of Carers is addressing this important area through the establishment of a network of Cafés des Aidants. Cafés des Aidants are held in a friendly, social, café-like environment with the goal of providing carers with a brief respite and opportunity to access psychosocial support. Cafés des Aidants are gatherings that carers can attend by themselves and experience a sense of belonging, normality, freedom and relief. Organized by local health and social organizations, Café des Aidants are facilitated by a social worker and psychologist with knowledge of and expertise in carers' emotional and social issues. The goal of Cafés des Aidants is to provide a positive space for carers to talk, share, learn and exchange with professionals and others in similar situations.

* A carer, caregiver or family carer is an unpaid individual, such as a family member, neighbour, friend or other significant individual, who takes on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. The terms caregiver, family carer and carer are used interchangeably by IACO members.



Embracing Carers is an initiative led by Merck KGaA, Darmstadt, Germany, in collaboration with leading caregiver organisations around the world, to increase awareness and action about the often-overlooked needs of caregivers. Learn more at www.embracingcarers.com.



The International Alliance of Carer Organizations (IACO) is a global coalition of 15 member nations committed to building a global understanding of and respect for the vital role of family carers. Recognised as an official NGO by the United Nations, IACO works to improve the quality of life and support the needs of carers, through international partnerships and advocacy. Learn more at www.internationalcarers.org.

DEVELOPMENT AND IMPLEMENTATION

The first café in France was hosted in 2003 and they continue to develop across the country through the support of the French Association of Carers. Cafés are typically held once a month in an easily accessible community setting such as a library, restaurant or bistro. Cafés are coordinated and hosted by local organisations that are members of the French Association of Carers, which include hospitals, health agencies, municipalities and community support centres. The hosting organisation plans and arranges the event details, organises specific activities, arranges refreshments and coordinates attendance of a social worker and a psychologist. Every Café des Aidants is organised around a theme and includes the following components:

- **Accessing information:** A presentation is made on themes around caring relationships, such as home support, relationships with care team, balancing work and care, self-care and rights of carers. The theme is selected to focus on available information and practical supports specifically for carers, not the condition of the person they are caring for.
- **Sharing experiences:** Opportunities are provided for carers to mingle, get to know each other and share personal experiences and insight.
- **Emotional and psychological support:** A psychologist and social worker listen to carers' concerns, help them identify and understand their feelings and behaviours, and equip them with coping strategies.

To ensure the program's consistency and quality across France, the French Association of Carers has developed a fundamental philosophy, approach and delivery model that must be followed by local organisations in planning, organising and conducting a Café des Aidants in their community. Agreement to host a Café des Aidants requires an annual commitment that includes the following key elements:

INITIATION

- Creation of a partnership agreement between the French Association of Carers and the hosting organisation outlining respective roles and responsibilities
- Allocation of human resources: 1 psychologist (3 hours/month), 1 social worker (3 hours/month), 1 program manager (2 hours/month)
- Agreement to foundational requirements including:
 - A commitment to the program's philosophy and methodology
 - Membership in the French Association of Carers
 - Completion of a 2-day training for Café facilitators (psychologist and social worker) addressing: (i) the profile and needs of carers, (ii) the program's philosophy and objectives and (iii) simulation exercises

IMPLEMENTATION

- Selection of location that is easily accessible with parking, in a social non-medical setting
- Arrangement for café to take place at least once every 2 months, 2 hours per session
- Open invitation to all types of carers
- Facilitation of café by a trained psychologist and a social worker
- Identification and approval of themes and topics for the planned cafés over a 12-month period

COMMUNICATION

The French Association of Carers supports the hosting organization with a communication/marketing toolkit that includes:

- Official Café des Aidants logo and program name, "Café des Aidants of (city/territory)," to be used on all materials
- Key messages including philosophy, features and benefit statements
- Customizable flyers and posters to facilitate event promotion and awareness
- Templates for local press releases directed at local media and community news channels
- Suggestions for community collaboration and partnership building to support an all-inclusive event

EVALUATION

Use of the French Association of Carers' evaluation strategy that includes annual measurement of input indicators (carers, types of content, facilitators) and outcome indicators (carers' and participants' satisfaction)

ADAPTATION

Participation in an annual one-day training and the French Association of Carers' Annual General Meeting to exchange experiences and lessons learned among Café des Aidants organisers and create new plans for future needs

DISSEMINATION AND IMPACT

Since 2012, the number of Cafés des Aidants has grown exponentially, starting with 16 cafés in 2012, 140 in 2017 and 190 in 2018. Located in communities across France, the Cafés des Aidants are dedicated to supporting the well-being of carers by providing much-needed emotional and social supports. To measure the effects of this exciting program, in 2016 the French Association of Carers commissioned a formal evaluation of the direct and indirect impact of attending Cafés des Aidants on the carers and the caring relationships. Conducted by external consulting firm KIMSO through the financial support of AG2R LA MONDIALE (a retirement pension fund), the evaluation was undertaken in two phases:

- **Phase 1** (October—December 2016) – Qualitative survey with 56 semi-structured interviews held with carers (26), organisers (11) and facilitators (19). Participants were recruited from 11 cafés across France who have run the program for a few months to as long as ten years, representing urban and rural regions.
- **Phase 2** (January—March 2017) – Using the key elements of the qualitative survey, a quantitative assessment (provided in electronic and hardcopy formats) captured carers' feedback and satisfaction following attendance at a Café des Aidants. A total of 140 locations were included in this phase, generating responses from 240 carers.



"I realise I wasn't the only one in this situation."

Outcomes and Experiences of Cafés des Aidants®

Who attends?

85%
women



60%
visit regularly
for over a year



58%
provide care for a relative
with chronic disease



70%
over 60
years old



45%
provide care
for spouses



Carers are not alone

The social element of Cafés des Aidants helps carers gain a sense of normality.



82% found socialising with others brought them comfort.

88% of carers shared that the café has helped them realise that they are not alone.

91% felt the café was a safe place to express themselves without fear of being judged.

An **inclusive social hub**, Cafés des Aidants are a welcoming place for carers even after their caring role has ended.

Carers are connected

Building and reinforcing relationships through communication, understanding and respect is a common benefit of attending Cafés des Aidants.



66% attended the café to speak with and learn from health care professionals.

67% shared that their relationship with the care recipient has improved since attending the café.

78% felt recognized in their role as a carer.

For the health care professionals, facilitating the Cafés des Aidants has given them the opportunity to **better engage** with carers and improve their knowledge of carers' lived experiences.

Carers are recognised and empowered

The interactive format of Cafés des Aidants helps carers realise their value and acknowledge their own needs.



42% reached out for services to support their daily caring activities.

43% took time for personal activities for themselves.

72% felt better about their carer's role and identified positive aspects of being a carer.

Cafés des Aidants are a **source of information** for carers—whether with or from others—including learning how to cope, access external supports and ask advice from other carers and health professionals.

"I want to find support and exchange information about things that could help me to understand better my relative's situation."

ELEMENTS FOR SUCCESS

While each Café des Aidants is customised and adapted to meet the unique requirements of the coordinating organization and carer attendees, a number of core elements are required for successful events. These include:

- **Carer focused:** Program content and discussion themes must consider carers as the primary client and make the carer feel recognised and embraced.
- **Multi-component:** An assortment of experiences that address carers' needs for peer support, respite, information and counselling should be incorporated into the program agenda.
- **Accessibility:** A relaxed, friendly atmosphere where carers feel confident to be themselves cannot be underestimated. This includes consideration for parking, privacy and cost to attend.
- **A trusted program:** A respected brand, Cafés des Aidants establishes program credibility and ensures all cafés are planned, coordinated and hosted with the highest level of quality. Facilitators must be trained.
- **Community partnerships:** Collaborating with community organisations with shared visions to recognise and empower carers helps to create a sustainable approach to hosting cafés and providing necessary supports after the events.

“I discovered possible supports near my home.”

FUTURE OPPORTUNITIES

Although many carers in France have greatly benefited from attending a local Café des Aidants, the French Association of Carers recognises there are many individuals who do not identify themselves as carers and feel reluctant to take time for themselves. Additionally, carers may be in situations where it is not possible to attend a café because of the difficulty in finding alternative support for the care recipient.

Each caring situation is unique. To begin addressing the different circumstances of carers' lives, the Association is continuing to build partnerships with local organisations in many different settings where carers' paths may intersect (e.g. employers to organise the café as a lunch-and-learn). As the number of Cafés des Aidants increase, there are opportunities for collaborative learning among all stakeholders (organisers, facilitators and carers). More extensive evaluation that explores the impact of the program on health care demand, use and costs will reinforce continued investment in this innovative approach to supporting the emotional and social needs of carers. Cafés des Aidants program is also complemented by other support services offered by the Association to meet the diverse needs and preferences of carers.

“On a professional level, it's very rich; it makes us develop our caring skills and a carer's culture.”

The French Association of Carers is committed to working with others to enhance the program where necessary and ensure tangible benefits for all types of carers. As a member of the International Alliance of Carer Organizations (IACO), the French Association of Carers is delighted to share this innovative practice with other countries and encourages like-minded individuals to meet up at a Café des Aidants.

References:

1. Stewart-Brown S. (1998). Emotional wellbeing and its relation to health. Physical disease may well result from emotional distress. *BMJ (Clinical research ed.)*, 317(7173), 1608-9.
2. Hansen, T., & Slagsvold, B. (2013). The psychological effects of providing personal care to a partner: A multidimensional perspective. *Health psychology research*, 1(2), e25. doi:10.4081/hpr.2013.e25.
3. French Association of Carers. (2016). Caregivers: A Societal Issue. Available at https://www.aidants.fr/sites/default/files/public/Pages/la_sante_des_aidants_-_rapport_final_2016_-_ass._fr_aidants.web_.pdf
4. OECD. (2011). *The Impact of Caring on Family Carers, in Help Wanted? Providing and Paying for Long Term Care*. Paris: OECD Publishing. Available at: <https://doi.org/10.1787/9789264097759-8-en>.

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The French Association of Carers (formed in 2003) advocates on behalf of the more than 8 million carers in France. Our mission is to advocate for recognition of the role of carers, working with public authorities and representative bodies to address carer-related issues, directly support carers and promote carer spaces, train family and paid carers, and promote best practices in caregiving.

For more information on the programme, contact: aide@aidants.fr | www.aidants.fr | [@AssoAidants](https://www.instagram.com/AssoAidants)