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Fact Sheet On Episodic Time Off (EPTO)

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Fact Sheet On Episodic Time Off (EPTO)

I. What are the trends among workers that illustrate the need for EPTO?

Workplace Flexibility 2010 has coined the term “Episodic Time Off” or “EPTO” to describe the type of workplace flexibility needed to address the recurring need for time off — sometimes regular, sometimes sporadic, sometimes foreseeable, sometimes not — for which Short Term Time Off is insufficient and which a Flexible Work Arrangement cannot resolve. Evidence illustrates that across the lifespan, for a variety of reasons, the need and desire for EPTO are great.

- There are many workers with disabilities or chronic or other medical conditions currently working in the labor force who may need EPTO; these populations are expected to grow as the workforce ages.
  - 58 million adults, more than one third of adults age 18–65, have at least one chronic condition. It is estimated that by the year 2020, half of the U.S. population will have at least one chronic condition and 25% will be living with multiple chronic conditions.¹

  ![PROPORTION OF ADULTS AGE 18–65 WITH CHRONIC CONDITIONS, 2000]

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>No chronic conditions</td>
<td>113M</td>
</tr>
<tr>
<td>1 chronic condition</td>
<td>39M</td>
</tr>
<tr>
<td>2 or more chronic conditions</td>
<td>19M</td>
</tr>
</tbody>
</table>

  - Between 2002 and 2012, the number of workers 55 years and older is expected to grow by 50%.²

  - Federal survey data indicate that 38.4% of people 65 to 69 years old report having a disability, compared with 19.4% of people 45 to 54 years old and 8.4% of people under 15.³
• Cancer is one disease that affects a large percentage of the working-age population. Many individuals
who are diagnosed with cancer are likely to try and remain at work after receiving their diagnosis and
during at least part of their treatment.
  — Recent estimates suggest 38% of women and 45% of men are likely to develop cancer.  
  — Nearly 88% of employed people who develop cancer wish to remain at work after their
diagnosis and during their care, despite debilitating treatments often resulting in transient or
long term limitations that can impact work.  
  — The graphic below highlights the distribution of dosing schedules among individuals receiving
chemotherapy treatment; EPTO would enable these workers to receive their necessary
treatment and maintain employment.

DOSING SCHEDULES AMONG INDIVIDUALS RECEIVING
CHEMOTHERAPY TREATMENT, 2004

29.70% Once every week
13.20% Once every 2 weeks
36.80% Once every 3 weeks
10.20% Once every 4 weeks
10.10% Other

— In a large study of chemotherapy patients and caregivers, 24% of patients reported
chemotherapy affected their paid time off of work, and 47% of caregivers reported taking time
off work to assist the patient with their medical appointment.

  — The same study found that doctor’s visits required almost three hours of the patient’s time
per visit, while chemotherapy appointments required almost 6 hours of time and laboratory
appointments required approximately 2 hours of time.

  -- Antibiotic treatments for chemotherapy-induced conditions averaged approximately 2.5
hours per visit.

  -- In addition to the time required of patients, their caregivers also spent approximately
2 hours accompanying patients to doctor’s visits and almost 4 hours accompanying
patients to chemotherapy appointments.

  — Studies indicate that lost paid work time, among other barriers, may make cancer treatment
particularly burdensome.

• In addition to cancer, there are many other chronic conditions that affect large portions of the
working-age population and/or their dependents. For many of these conditions, EPTO, available on
both an as needed and recurring basis, would enable workers to better manage both acute episodes
and persistent health needs while maintaining employment.
Currently, one in five adults, nearly 43 million, report having doctor diagnosed arthritis.\textsuperscript{10} By 2030, an estimated 67 million adults will have doctor diagnosed arthritis, and working age adults (45–64) will account for almost one third of all cases.\textsuperscript{11}

According to another earlier study, arthritis results in 44 million ambulatory care visits per year, including 38.9 million visits to physicians' offices, 2.9 million visits to outpatient departments, and 2.2 million visits to emergency room departments.\textsuperscript{12}

In 2003, nearly half a million U.S. residents were under treatment for end-stage renal disease during the calendar year. Of those receiving dialysis treatment, 91% received hemodialysis treatment at a dialysis center.\textsuperscript{13} Most patients receive hemodialysis treatment three times a week for 3 to 5 or more hours each visit.\textsuperscript{14}

Of dialysis patients aged 18–54 years old, 1 in 5 is currently employed full or part time.\textsuperscript{15}

-- Another study revealed that of dialysis patients who continued working during their treatment, 90% were using peritoneal dialysis (PD).\textsuperscript{16} If workers are provided EPTO, this form of treatment can be done at the home, allowing workers the ability to balance work and their treatments.

-- Among the 80% of working-age dialysis patients not employed, this may be attributed to the difficulty in working while needing treatment if EPTO is not available, since fewer than 20% of dialysis facilities offer treatment after 5 p.m.\textsuperscript{17}

According to the National Multiple Sclerosis Society, approximately 400,000 people in the United States have multiple sclerosis.\textsuperscript{18} Depending on the type and progression of the disease, many multiple sclerosis patients suffer acute exacerbations, or “flare ups.”\textsuperscript{19}

A flare up can range from mild to severe and usually lasts from several days to several weeks, although they may extend into months.\textsuperscript{20}

Most multiple sclerosis specialists recommend a 3–5 day course of high-dose intravenous steroids to treat an acute attack.\textsuperscript{21}

According to a nationally representative survey, approximately 16% of the labor force suffers from major depressive disorder, frequently referred to as depression, at some time in their lives.\textsuperscript{22} Moreover, it is rare that people with depressive illness endure only one episode of major depression. EPTO may be necessary for workers with depression and other mental illnesses to acquire necessary treatment.

According to the American Psychiatric Association, the optimal frequency for psychotherapy treatment has not been rigorously studied. The frequency of outpatient treatment during the acute phase of depression generally varies by patient status but ranges from once a week in routine cases to as often as several times a week. Treatment during the maintenance phase can range from as low as once every two to three months to as high as multiple times a week.\textsuperscript{23}
• Many workers need EPTO in order to provide care to family members who have chronic conditions or disabilities.
  
  — There are 44.4 million American caregivers age 18 and older who provide unpaid care to an adult 18 and older. Just over half (51.8%) of all caregivers in the United States are employed full time, with almost two-thirds (64%) employed at least part time.\textsuperscript{24} Often, the person receiving care has some chronic condition that may flare up, or require periodic medical visits.

  ■ Among caregivers helping someone between the ages of 18–49 years old, the most common problem or illness of the person they care for is mental illness or depression.\textsuperscript{25}

  ■ Among caregivers who provide assistance to someone 50 or older, 15% say the main problem or illness of the person they care for is aging. Other illnesses commonly cited as the main illness of the care recipient include: diabetes, cancer, and heart disease.\textsuperscript{26}

  — Asthma is the most common chronic disorder in childhood, currently affecting an estimated 6.2 million children under 18 years of age.\textsuperscript{27} This disease can frequently be managed with recurring treatment and disease management. Nonetheless, acute and unexpected attacks do occur.

  ■ Among children under the age of 15, asthma is the third leading cause of hospitalization.\textsuperscript{26}

  ■ In 2002, over half a million emergency room visits were due to asthma in those under 15.\textsuperscript{29}

  — In a small study of parents with children ages 7 to 16 years old suffering from chronic conditions:

  ■ Nearly 20% of parents reported having to take time off from work to accommodate appointments,\textsuperscript{30}

  ■ over 10% reported needing to attend medical appointments one to two times per month, while over 20% reported needing to attend medical appointments less than one time per month,\textsuperscript{31}

  ■ and 16% reported that their child had required at least one emergency room visit for pain control.\textsuperscript{32}

  — According to a national survey, there are approximately 9.4 million children in the United States with special health care needs. The survey revealed that 1 in 5 households has a child with special health care needs. The medical needs of these children can affect the needs of employed parents.\textsuperscript{33}

  ■ For example, of children with special health care needs, 74% required prescription medications, 45.6% required more medical care, mental health, or educational services than what is usual for most children of the same age, and 29% required emotional, behavioral, and/or developmental services.\textsuperscript{34}

  ■ Among parents of children with special health care needs, 17% reported having to cut back on work and 13% stopped work entirely due to their children's needs.\textsuperscript{35}

  ■ Depression is one of many conditions that affect children with special health care needs. According to the National Mental Health Information Center, at any point in time 10-15% of children and adolescents have some symptoms of depression.\textsuperscript{36}
According to an analysis of a national sample of commercially insured beneficiaries, the overall prevalence of antidepressant use among children increased by 49% between 1998 and 2002.\textsuperscript{37}

For those children who are taking antidepressant prescription medications, the FDA recommends the following regarding frequency of doctor visits after a child or adolescent starts on an antidepressant: once a week for four weeks, every 2 weeks for the next month, at the end of their 12th week taking the drug, and more often if problems or questions arise.\textsuperscript{38}

II. How does the current structure of work, benefits, and laws respond to the needs of individuals needing EPTO?

Some employees have access to needed time off through either voluntary employer provided benefits or other existing legal programs. However, available data indicates that the provision of time off is sparse and disparate, and even amongst those with some form of access, current benefits are inadequate in meeting the needs of the majority of employees.

- Despite the growing desire and need for time off, a recent survey indicates that the amount of paid vacation, paid sick days, paid time off plans, and paid personal days may be decreasing.\textsuperscript{39}

- Among American workers, 59 million, or 49\% of all American workers, have no paid sick leave coverage.\textsuperscript{40} This means these workers cannot rely on sick leave to assist them in dealing with routine or chronic health care needs. (NOTE: This data does not distinguish between STO and EPTO needs.)
  - Among full-time workers, 38 million (40\%) do not have access to paid sick days.\textsuperscript{41}
  - Among part-time workers, 21 million (84\%) do not have access to paid sick days.\textsuperscript{42}
  - Among parents, two out of three do not have access to paid sick days consistently while they work.\textsuperscript{43}

- Only 1 in 3 workers, 33\% of workers, have paid sick leave that may be used for doctors’ appointments; this leaves almost 82 million workers with insufficient paid time off to take care of routine and acute medical care.\textsuperscript{44}

- The Family and Medical Leave Act of 1993 (FMLA) permits eligible workers to take up to 12 weeks per year of unpaid time off for medical or for family care reasons. However, only about 60\% of employees in the U.S. work for employers covered under the FMLA. The majority of workers (78\%) report they would be financially unable to take advantage of unpaid FMLA leave.\textsuperscript{45}
  - For those employees who are covered, eligible, and able to utilize the FMLA, the law specifically authorizes “intermittent leave” or leave that can be taken for a few hours or days at a time.\textsuperscript{46} The trends among leave takers illustrate that “intermittent leave,” a form of EPTO, is used to manage both routine and unexpected or sporadic needs.
    - According to a 2001 survey of employees and establishments, approximately 20\% of all leave taken under the FMLA is intermittent.\textsuperscript{47}
    - About a fourth of leave takers, 27.8\%, took intermittent leave in the 18 months before the survey.\textsuperscript{48}
Among individuals who reported taking intermittent leave at least one time in the 18 months before the survey, almost 50% indicated that at least half of their total leave was utilized on an “as needed” basis.49

When asked about employees’ longest leave, about 20.8% of these leaves were intermittent. More specifically, among leave takers whose longest leave was intermittent, 86.6% of leaves were taken on an “as needed” basis while 13.4% used intermittent leave on a regular routine schedule.50

Analysis of the 2001 FMLA survey data also illustrates a strong relationship between the reason for one’s leave and the use of intermittent leave. These findings indicate that intermittent leave is often used to enable workers to balance work and personal and/or dependent health care needs.

For example, employees whose longest leave was to care for an ill family member (either a child, spouse, or parent) were about twice as likely to take intermittent leave as those using leave for other reasons.

Also, the most frequently cited reason for one's longest leave was one's own health. However, among those taking leave for this purpose, intermittent leave was relatively uncommon (15%). But, intermittent leave was quite common among those whose longest leave was to care for an ill child (39.5%), ill spouse (30.9%), or ill parent (33.1%).

Based on a 2001 Department of Labor survey, the majority of covered businesses reported that intermittent leave has had no impact on productivity (81.2%) and profitability (93.7%). When broken down by size, smaller establishments (250 or fewer employees) were more likely to indicate a slight negative impact.51 By contrast, business trade associations have reported that their members have had significant difficulty implementing the FMLA’s intermittent leave provisions.52

Of 22.4 million caregivers, the majority are employed and balancing work and caregiving responsibilities at the same time. In some instances, the burden of caregiving often forces workers to give up work entirely (6.4%), or take a leave of absence (11%). Consequently, analysis regarding the cost of caregiving highlights that replacing employees is one of the most expensive costs associated with caregiving for business, costing nearly $5 billion per year.53 Moreover, this charge does not include the cost to family stability or other social programs when workers are forced to withdraw from the workforce. The provision of EPTO might enable worker continuity, consequently diminishing employer and societal costs due to termination of employment.

Currently, there is very little data available regarding the availability and utilization of episodic time off as an accommodation under the Americans with Disabilities Act.
(Endnotes)


The Forum of ESRD Networks (2004, November). *Summary report of the End Stage Renal Disease (ESRD) networks’ annual reports, 2003*. Midlothian, VA: Author, p. 79. Retrieved August 2006, from http://www.cms.hhs.gov/ESRDQualityImprovementInit/downloads/Annual%20Report%202003.pdf#search=%22Summary%20of%20End%20Stage%20Renal%20Disease%20Networks%20Annual%20Reports%22 The data provided in this report is based on a compilation of data acquired from the 18 dialysis networks contracted by the CMS to serve as the liaison between the federal government and providers of ESRD services. The data represent over 300,000 dialysis patients.


Exacerbations are a sudden worsening of symptoms associated with multiple sclerosis or the appearance of new symptoms. Flare ups last at least 24 hours and are separated from a previous exacerbation by at least one month. The National Multiple Sclerosis Society. (2005).

The data for this study was acquired from the National Comorbidity Survey, which is nationally representative and designed to study the prevalence, causes, and consequences of mental illness and comorbidity between various psychiatric disorders. Marcotte, D.E., Wilcox-Gok, V., & Redmon, D.P. (1999). Prevalence and patterns of major depressive disorder in the United States labor force. *The Journal of Mental Health Policy and Economics* 2, p. 125.


American Lung Association (2005, July). This is based on National Hospital Discharge survey data from 2002 which was provided to the American Lung Association on special request to the National Center for Health Statistics.

American Lung Association (2005, July). This data is based on American Lung Association analysis of the National Center for Health Statistics 2003 National Hospital Ambulatory Medical Care Survey.

Lilley, C.M. (2000). Parent perceptions of the impact of chronic pain in children and adolescents. *Children’s Health Care* 29(3), p. 154. This study is based on a convenience sample of 43 parents of children and adolescents who had consecutively been referred to two outpatient treatment programs in Canada because of clinically significant distress or disability associated with chronic pain. The facilities draw from a large urban area and serve families from diverse backgrounds.


The survey defines children as those under 18 years of age who: need or use medicine prescribed by a doctor; need or use more medical care, mental health, or educational services than is usual for most children of the same age; are limited or prevented in ability to do things; need or get special therapy; and/or need or get treatment for an emotional, developmental, or behavioral problem. The survey included surveying and screening over 5,600 children in more than 3,100 households in each state. U.S. Department of Health and Human Services, Resources and Services Administration, Maternal and Child Health Bureau (2004). *The National Survey of Children with Special Health Care Needs (CSHCN) chartbook, 2001*. Rockville, Maryland: Author, Retrieved August 2006, from http://mchb.hrsa.gov/chscn/


39 The authors do express the caveat that this change might be accounted for by a change in methodology of the survey. Society for Human Resource Management (SHRM) (2004). 2004 Benefits survey report. Virginia: Author, p. 47. This data is a cohort study based on a survey of human resource representatives from 459 member organizations from both the public and private, for-profit and not-for-profit sectors.


49 Cantor, D., Waldfogel, J., Kerwin, J., McKinley-Wright, M., Levin, K., Rauch, J., Hagerty, T., & Stapleton-Kudela, M. (2001). p. 2–10, 2–11. Specifically, the data indicates about a fourth (26.4%) say “more than half” of their leave was intermittent, and nearly 20% (19.6%) report “about half” of their leave was intermittent. Collectively, this indicates that about half of the time taken among those reporting that they have taken at least one intermittent leave in the past 12 months was intermittent.


