



Students with IBD

A guide for primary,
secondary, and tertiary
educators



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Crohn's & Colitis Australia (CCA) is the peak body representing approximately 75,000 Australians with IBD.

CCA supports the IBD community through advocacy, online support, support groups, information forums, youth camp programs, and the Can't Wait Program.

Visit www.crohnsandcolitis.com.au for more information about CCA's programs and services.

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PART I: About this book

This book aims to help educators support students who have inflammatory bowel disease (IBD). It gives key information about Crohn's disease and ulcerative colitis, their physical and emotional impact on students, and their effects on various aspects of life. The goal is to help schools work with families in supporting and preparing the students for higher levels of education and greater independence.

As an educator, you will, at some time, probably have a student with IBD. In fact, IBD is often thought of as a "young person's disease" because its onset is typically between the ages of 15 and 35, although it can certainly be diagnosed at a younger age. It is therefore important to engage the school right from the start as an active partner in supporting a student with IBD. The school's involvement can help these students live normal lives, while lack of involvement and support from the school can lead to poor adjustment on the students' part, which can then lead to:

- difficulties completing work on time;
- diminished academic performance;
- difficulties sitting exams;
- difficulties maintaining relationships with school friends;
- difficulties participating in school activities (e.g., physical education, excursions);
- lack of confidence, motivation, or self-esteem; and
- issues relating to body image.

PART II: General information

What is IBD?

Inflammatory bowel disease (IBD) refers to a group of chronic inflammatory conditions that affect parts of the digestive tract, but most commonly involve the small and large intestines. The most common diseases are **Crohn's disease** and **ulcerative colitis**.

IBD affects the lives of approximately 75,000¹ Australians. Approximately 5,400 new cases are diagnosed every year², and new estimates show that by the year 2022, the number of people living with IBD will reach 100,000.³

What are the Physical Symptoms of IBD?

| Symptom or Sign | Crohn's disease | Ulcerative Colitis |
|---|-----------------|--------------------|
| Abdominal pain or cramping | ✓ | ✓ |
| Diarrhoea | ✓ | ✓ |
| Nausea/vomiting | ✓ | |
| Blood in the stool | ✓ | ✓ |
| Mucus in the stool | | ✓ |
| Lack of appetite and subsequent weight loss | ✓ | ✓ |
| Fatigue | ✓ | ✓ |
| Urgent need to move bowels | ✓ | ✓ |
| Fever | ✓ | ✓ |
| Arthralgias (joint pain) | ✓ | |

1. *Improving Inflammatory Bowel Disease Care Across Australia*, PwC, March 2013

2. *High incidence and prevalence of inflammatory bowel disease in Victoria; a prospective, observational, population-based Australian epidemiology study*, by Studd, Desmond, et al., 2012

3. *Improving Inflammatory Bowel Disease Care Across Australia*, PwC, March 2013

Children with IBD

IBD symptoms among children are often acute and require immediate management, but early disease management that keeps the symptoms under control will help the children understand and accept their condition.

Many people with IBD live very normal lives, but students with IBD will most likely experience a disruption to their education, extra-curricular activities, and social life. IBD can also disrupt their physical growth and maturity, especially during the critical stage of puberty and adolescence.

There's no cure, but...

- IBD is not fatal;
- it is not contagious;
- it is possible to have weeks, months, even years of remission;
- many with IBD have only mild or moderate symptoms that respond well to treatment.

Nonetheless, parents and educators need to remember that, for the rest of their lives, young people with IBD will need treatment, education, support, and acceptance.



Many children with IBD will go on to lead normal lives.

IBD IS NOT IBS⁴

IBS stands for irritable bowel syndrome, and IBD stands for inflammatory bowel disease.

*IBS refers to a set of symptoms (hence, **syndrome**).*

It is a “functional disorder where the gastrointestinal tract looks normal but does not function normally. It does not cause inflammation, nor does it cause permanent intestinal damage.”

*IBD is a **disease** that commonly involves inflammation of the large and small intestines. The chronic inflammation and subsequent damage result from the immune system attacking intestinal tissue.*

How is IBD treated?

Medication is prescribed for controlling inflammation, pain, and diarrhoea, and for replacing lost vitamins and minerals. Medications include:

- anti-inflammatory drugs (Mesasal®, Salazopyrin®);
- corticosteroids;
- immunomodulating agents;
- antibiotics;
- biologics (Remicade®, Humira®).

Side effects will vary with the type of medication. Reactions can include nausea, diarrhoea, skin rashes, acne, weight gain, change in appetite, and mood changes. **It is rare, however, for someone to experience all or even most of the side effects of any given drug.**

Liquid feeds (enteral nutrition) are used to supplement nutritional deficiencies, and are also a primary treatment in themselves, to the exclusion of other diet. They can be taken by mouth or through a nasogastric tube (which will be visible at school).

Surgery will be considered by doctors if medication is ineffective in managing IBD. Options are weighed against the patient’s age, general health, and extent of the disease.

How Does IBD Affect Diet?

Many people with IBD can tolerate all types of food and do not need to change their diet. During flare-ups, however, they might find it easier to tolerate a bland, low-fibre diet than a high-fibre one that will keep the intestines busy and active.



During flare-ups, a low-fibre diet can help ease symptoms.

“During flare-ups, our six-year old daughter, who has Crohn’s, avoids friends’ birthdays, as she knows she cannot eat what others have. She understands why we had to modify her diet, as she does not want the pain.”

Maria, parent

4. IBS vs IBD, www.digestionexpert.com/2010/11/ibs-vs-ibd

PART III: The school and the family working together

Toilet Access

Toilet access is a major concern of anyone with IBD. During flare-ups, he or she might need to go to the toilet urgently and frequently, often with little or no warning.

Among students with IBD, school can be a terrifying place when they really need to go to the toilet and:

- they are not near any facilities;
- they need to call attention to themselves to leave the classroom;
- they need to explain their situation to their teachers every time;
- they have to worry about the reaction of other students;
- they worry about embarrassing themselves.

Working out a toilet access plan is discussed on page 14.



Fear of embarrassment can be crippling to the student with IBD.

IBD is a complex and highly individual condition. It is important that the student's particular needs are discussed openly and candidly with the school principal, year-level coordinator, homeroom teacher, and/or school nurse during a face-to-face meeting soon after a diagnosis, or at the beginning of the school year. Depending on the situation, it might also be useful to meet with the student's doctor/s.

The School's Responsibilities to Students with IBD

When it comes to supporting students with IBD and other conditions, schools use, as their guideline, the **Disability Discrimination Act 1992**.

Is IBD a Disability?

Because IBD is a chronic condition that can affect a person's daily activities, the government classifies it as a disability that is subject to the Disability Discrimination Act 1992.

The Australian Human Rights Commission, in its guide to the Disability Discrimination Act 1992, states that:

"Educators must offer a person with a disability the same educational opportunities as everyone else. This means that if the person meets the entry requirements of a learning institution, he or she should have just as much chance to study there as anyone else."

(www.hreoc.gov.au)

PART IV: The primary school years



Open communication between the school and the family is essential in helping the student cope.

The Student Health Support Plan

The first step in helping a student with IBD is developing a **Student Health Support Plan** in consultation with the family and clinical team. The plan must document the student's health needs and how the school will help. It should be made accessible to the staff, and reviewed whenever there is a significant change in the student's condition or treatment.

Developing the plan involves:

- identifying the student's health condition;
- identifying what type of support will be needed at school (e.g., help with medication);
- determining who at school can provide support (e.g., teacher, counsellor);
- determining how the student's health is likely to affect school attendance and participation;
- regularly monitoring and reviewing results to ensure that the plan is relevant and up-to-date, in relation to the student's condition.

See **Appendix: Student Health Support Plan (Guide)**⁵ for guide questions in developing the plan.

Eight-year-old Chris was diagnosed with colitis when he was just 4. He's now in Grade 2 and needs regular treatment and medication to manage the symptoms of his active disease.

Physical Impact

A major physical impact of IBD on children up to 12 years old is **delayed growth**. This means that the student might be shorter, thinner, and/or smaller than his peers.

How does IBD affect a child's growth?

Factors delaying growth — and puberty — in IBD include:

- inadequate nutritional intake due to active disease;
- corticosteroids, especially if taken in high doses and over long periods.

Once the symptoms are managed and the nutritional intake improves, the child's height and/or weight should improve.

Other Physical Effects

Children with active disease might seem frail, and sometimes listless and lacking in energy. And while they might actually *look* well at times, they still could be suffering from other symptoms, such as cramps and lack of appetite.

Teachers can help by giving such children some leeway when they seem sluggish in their movements, slow in their work, or hesitant in joining activities such as sports, excursions, and camps.

5. Based on The Royal Children's Hospital Melbourne template

Emotional Impact

Many children with IBD do not completely understand their condition or what they are going through, and this can affect them emotionally.

Key emotional issues at this time include:

- **Embarrassment, frustration, and anxiety** when the child needs to go to the toilet urgently, often with very little warning.
- The child's growing awareness of himself and other children might make him feel **self-conscious about body issues**, real or imagined, including weight, height, skin, hair, and general appearance. He might become fearful of being teased, and withdraw from social activities.
- **Fear of not doing well at school.**
 - If too many school days are missed, due to illness and/or hospitalisation, the child might feel too helpless to catch up with school work.
 - He might be unable to pay attention at school, especially if he is exhausted or unwell.
 - He might feel anxious about others teasing him about his inability to keep up.
- **Missing out on out-of-school activities** (e.g., birthday parties) can be another concern, especially since these are opportunities to socialise outside school.
- **Fear of bullying** is a very real concern. Children can be careless and cruel, and can target anyone who is different. Signs that a child, especially one with a chronic illness, is being bullied at school include:
 - depression and anxiety;
 - fits of crying, tantrums, anger;

- not wanting to go to school, or withdrawing from social activities;
- increased occurrence of symptoms when at school;
- worsening of symptoms due to stress.

How Can the School Help?

1. Develop a Student Health Support Plan As mentioned on page 10, this should outline how the school will meet the child's health-care needs at school. It should also cover:

A. Maintaining the student's dignity and privacy.

- Conveying information about the student's condition in a straightforward and respectful manner.
- Giving the student a private place where medication can be administered.
- Seating the student near the classroom door, for an easy and least disruptive access to the toilet.

B. Keeping the student safe and comfortable.

- Having a system in place should the student fall seriously ill while at school.
- If needed, giving the student's class relevant and age-appropriate information about IBD, to help them understand what their classmate is going through.



Support from the school goes a long way in making students' lives easier, despite their condition.

C. Enhancing the student's learning experience.

- Involving and including the student in school activities, however possible.
- Tailoring the curriculum and school work to match the student's needs. This makes catching up easier when school days are missed, and enables the student to study at home or in hospital, if feasible.

2. Develop a Personalised Learning Plan that outlines how the student will be assigned lessons, school work, and tests. Keeping in mind possible missed class time and long periods away from school (due to flare-ups and/or surgery), the plan should organise the school work so that more important lessons are given priority.

"All the operations I had were mostly painful but I got used to them. It does have an impact on my schooling. Last year I missed 40 days of school, but I caught up on the work."

Ned, age 11

3. Assign a teacher or staff member who can serve as the main liaison between the school and the child's family.

This gives the family a specific person to go to who would know about the child's needs and situation, and who can be an ally and advocate at school.

4. Work out a toilet access plan that will help the child use the facilities when needed. This might include:

- giving the child a permanent pass to go to the toilet during school hours;
- giving the child access to use the teachers' toilet facilities, in case the students' facilities are unavailable or otherwise inaccessible;

- giving the child privacy from other students when he or she is in the toilet, to avoid embarrassment during noisy bowel movements; and
- having the school nurse or sick-bay officer help in areas of medication, bathroom concerns, and other health issues.

5. Make allowances for the student's need to have meals or snacks at different times of the day. Depending on the student's treatment program, medication schedule, and ability to handle food, he or she might need to have staggered meals, or have some food outside lunchtime or recess.

6. Do not be over-protective. Allow the child adequate freedom to do normal things at school. This boosts confidence and develops independence.

IBD need not pre-determine a person's identity or achievements.

7. Do not assume that the child cannot participate in activities. Unless ill, in hospital, or otherwise fatigued, a child with IBD can still live a normal life and enjoy normal school activities. Keep in mind, however, that some children might push themselves when they are ill, to avoid seeming different from their peers. An honest and open communication with the family would be helpful in gauging the child's actual ability to participate in activities.



Students with IBD can do many, if not all, things that healthier students can do, in and out of school.

PART V: The high school years

"I still play a lot of sport and I find going to and playing basketball and netball with my friends is great. I also like knee-boarding and wake-boarding behind dad's boat. Mum and I have decided to just do what we can and to keep planning, otherwise we may not get to go places."

Georgia, age 11



A child who is being bullied needs to know that his school and family are supporting him all the way.

8. Watch out for the bullies. It is hard to thrive in a bullying environment, and children can be scarred more deeply by bullying than by any disease. If you suspect bullying, you will need to take a proactive approach in teaching effective coping strategies and reinforcing the school's anti-bullying policies.

9. Encourage the student to be increasingly responsible and independent. Depending on age and ability, the student should take responsibility for certain aspects of his or her own care. For example: young students can bring their own medication to school; older students can manage conflicts in their schedule involving medical appointments and class time.

10. Encourage open communication. Bowel-related topics can be extremely embarrassing to discuss, which only serves to isolate those who have IBD. Give your student opportunities to talk, and encourage open communication.

Tina is 14 and has Crohn's disease. Her disease is moderate for the most part, and she finds that her symptoms are easily manageable with medication. She's still waiting for puberty to kick in, though, and still looks like she's three years younger than her friends.

Physical Impact

Most of the physical impact that IBD has on adolescents are carried over from their younger years: weight loss, fatigue, joint pain, abdominal pain, and diarrhoea.

Other physical manifestations of IBD can include **surgical scars** from previous procedures, or an **ileostomy bag**. These can make a young person feel extremely uncomfortable in situations where others might see it, such as during PE or at camp.

Adolescents might also be concerned about **delayed puberty**. Girls might look younger, smaller, shorter, and less mature than their peers. Boys can look thinner, shorter, less masculine, "puny," and generally less developed than the healthier boys. All this can make the affected students, especially the boys, targets for bullying from the more physically mature students at school.

Emotional Impact

Adolescence is a time of extreme self-consciousness and insecurity. For adolescents with IBD, this time can be far more challenging.

Those with IBD can experience **depression and anxiety** far more than their peers, because of their delayed physical development and general physical appearance (acne, "moon face" resulting from corticosteroids, weight loss or gain), and the constant stress of living with a chronic illness.

"When I was 14, I was put on mesalazine and steroids, which made me really fat...and the first thing my friend said to me when I got back to school was, 'I thought people lost weight when they went to hospital.' It was ridiculous because I had always been thin. It made me very self-conscious, and I got teased at school a lot."

Luke (diagnosed with Crohn's disease at age 14)



Boys with IBD might feel inferior because they are not as strong or as big as their peers.

Furthermore, a study⁶ has found that the more depressed a chronically ill young person is, the more he or she is likely to **stop complying with medication**, especially if:

- the disease is inactive;
- the medication is perceived to be ineffective;
- the regimen is becoming too complicated; and
- the side effects are too unpleasant (e.g., acne, "moon face").

While non-adherence to medication is largely an issue for the student's family and doctors to handle, you can play a role in averting such risky behaviour (see page 20).

Teens with IBD might also suffer from **a sense of isolation** and being left behind by their peers. Besides feeling excluded from some activities, they might feel

they are being left behind in terms of physical development. Boys in particular might feel inferior because of their reduced strength, shorter stature, and smaller build compared to their peers. Girls tend to worry about peer acceptance, relationships with their friends, and body image.

Teens with IBD can become even more **self-conscious** than their peers, especially if they look younger and different. This makes it more difficult for them to socialise and participate in activities.

All this, on top of the other developmental changes that all teens go through, can make a young person with IBD feel repeatedly **frustrated** and **alienated**, and end up with **low self-esteem**.

How Can the School Help?

- 1. Develop and implement a toilet access plan.** In addition to tips shown on page 14, a school map with toilets for students and staff especially marked would be very useful.
- 2. Be sensitive to the student's needs.** Besides health and medical needs, these include the need for inclusion and acceptance; the need for discretion to minimise embarrassment; and the need to be treated as a normal teen.

"Before we told the school about my daughter's IBD, her friend would cover for her whenever she needed to go [to the toilet at school]. Naturally, this affected her sense of confidence and made things difficult at school."

Rose, parent

- 3. Include the student in all activities.** See page 15.

6. IBD in Adolescents: What Problems Does It Pose?
Lu & Markowitz, 2011

4. Be conscious of risky behaviour. Adolescents are prone to taking risks as they try to test their limitations. Such risks include having unprotected sex, abusing alcohol, and taking illicit drugs. Adolescents with IBD might also decide to discontinue their medication without consulting their physicians.

Taking risks is part of growing up, but there are healthy risks (e.g., trying new school activities, making new friends, travelling) and unhealthy risks (such as those described above). Students with IBD must be taught that taking risks does not mean endangering one's life.



Making new friends is both healthy and helpful to any adolescent.

5. Allow for flexibility. The student who is coping with an active disease needs more time and space to complete school work and sit exams. The following points might be useful to keep in mind:

- The **Personalised Learning Plan** (see page 14) can help monitor progress and ensure that school work is tailored to meet the student's current situation.
- The year-level coordinator should engage with other teachers to achieve a realistic volume of work for the student at any given time.
- When a student is going through a bad patch, less work should be assigned until the situation improves. Consider planning school work prioritised by importance, keeping in mind that simply extending deadlines do not always work (as they can just add to the pressures on the student).
- Consider breaking down tasks into smaller manageable parts, with interim (but flexible) deadlines set out to complete the work.
- With core subjects such as Languages, Maths, and Sciences, consider using resources that can be accessed from home or hospital.
- Keep in mind that there are government provisions for students who are ill or experiencing personal hardships. The provisions allow these students to make alternative arrangements for completing their school work and sitting exams (e.g., Victorian Curriculum and Assessment Authority Special Provision; South Australia Special Provisions in Curriculum and Assessment Policy; Queensland's Policy on Special Provisions for School-based Assessments).

PART VI: Tertiary education (the early years)

STEVE, 17, has just finished high school and is about to start his first year at university. His colitis has been inactive for a year now, and he has found a part-time casual job that works well with his routine. As his first day at university approaches, he is starting to get ready for the adult years.

Physical Impact

Over the years, Steve has learned to manage his symptoms, which include fatigue, diarrhoea, cramps, and pain. He has also learned to handle most situations relating to his IBD. He has something to eat before going out, avoids foods that might trigger his symptoms, manages his stress, and keeps a realistic work/rest balance.

As Steve gets ready for uni, his stress level will most likely increase as he juggles studies, health, work, and other aspects of his life, such as sports, relationships, and other activities.

Emotional Impact

Young people with IBD who are about to start tertiary education have many new things to deal with, and might find that stress worsens their symptoms. It is therefore important that they thoroughly prepare well ahead of time, to lessen the stress later on.

These young adults need to prepare for tertiary education as independently as they can. In terms of their IBD, they have to:

- schedule and attend medical appointments;
- adhere to their medical regimen;
- keep themselves healthy through diet, exercise, and rest;

- manage their time between classes, assignments, family, part-time work, social activities, and rest and relaxation;
- advise the tertiary institution of their condition upon enrolment, and not wait for a crisis;
- create and maintain a support network on campus to help them manage their condition and possible flare-ups; and
- advocate for themselves with professors, tertiary institution staff, the student disability services team, and other parties who can help.

How Can the Tertiary Institution Help?

The institution's student centre, student liaison officer, or disability officer are there to help students with chronic conditions take advantage of opportunities available to all students.

- They help students advise professors or lecturers of their condition, so that if classes are missed due to illness or hospitalisation, there would be no need to continually explain the situation.
- They can offer counselling and guidance relating to health, social adjustment, work load, academic progress, stress, and anxiety.
- They offer flexible options for sitting exams (see page 25).



Sitting exams can be made more manageable by making arrangements beforehand.

- They can give access to secure storage areas where medication and food can be stored with relative discretion.
- They can give information regarding the types of food available at the cafeterias.

The National Disability Coordination Officer Program (NDCO)

NDCO helps tertiary-level students with disabilities overcome barriers to a successful completion of post-school education, training, and subsequent employment. Operating in 31 regions in Australia, NDCO provides information, coordination, referral services, and possible funding for people with a disability who are interested — or enrolled — in post-secondary education and training.

For more information, visit www.innovation.gov.au and look up National Disability Coordination Officer Program.

Helping the Tertiary Student in the Real World

If you are a disability officer or student counsellor trying to help a student with IBD manage daily life, here are some things that you can say.

Course Work Deadlines

Allowance for coursework extension should be covered in your Personalised Learning Plan. When you negotiate an extension, be realistic about the time you need to recover and how much work you can do when while you are still unwell and recovering.

In the meantime, try to get to know one other person in every class whom you can talk to should you miss a session and need to catch up.

Sitting Exams

If pre-exam anxieties trigger your symptoms, try to pace yourself and find ways of relaxing before any exam.

Based on your Personalised Learning Plan, a medical certificate from your doctor, or any arrangement you might have with your professor or lecturer, you will probably be able to make advance arrangements regarding exams. These can include sitting close to the exit nearest the toilets, having someone to accompany you if needed, and requesting extra time if needed.

If you find you are completely unable to sit an exam, you might be able to defer sitting it until you are better, without having it affect your grade.

“Exams are stressful enough without having Crohn’s disease and worrying if you’ll make it to the toilet in time – never mind in front of 200 students! Thanks to [my university’s Disability Officers], throughout my degree, all my exams will take place in an individual room with a toilet only a few metres away. I will have extra time to complete my exam to allow for toilet breaks.”

Leurissa, law student

Social Life on Campus

Campus life offers many opportunities to meet different people and make friends. If you are not having a flare-up and your symptoms are under control, there is no reason you should not be able to enjoy your time on campus.

APPENDIX: Student Health Support Plan (Guide)⁷

Dating and Relationships

Dating is a tricky business. It becomes even trickier when a chronic illness is involved, especially if the illness is IBD.

"I've gone out with people before who would run far away at the first mention of 'bowel disease.' I tend to be honest and not hide, but I still have to learn the right balance between honesty and giving too much information too soon." Lisa, 17

The best thing to do is to get to know the person first, then see how you get along with each other. Consider 'spacing' the information that you share, easing into more details as your comfort level dictates.

On a first date, for instance, you might say that you have an upset stomach that is making you feel out of sorts and not very interested in the meal. This vague reason will come in handy should you need to end the date early because you are tired or unwell.

Intimacy and IBD

Unless you are having a flare-up or are otherwise unwell, there is no reason why you cannot be physically intimate with someone you care about. If, however, you feel unable to manage a physical relationship, talk to your specialist, your GP, a gynaecologist, or even a psychologist.

Whatever your situation, practicing safe sex is a must. This is true for everyone, and not just for those with a chronic illness.

This plan outlines how the school will support the student's health care needs, based on health advice received from the student's medical/health practitioner. This form must be completed for each student with an identified health care need. This plan is to be completed by the principal or nominee in collaboration with the parent/carer and student.

The plan should include the following information:

Student's name:

Date of birth:

Year level:

What is the health care need identified by the student's medical/health practitioner?

Other known health conditions:

When will the student commence attending school?

Detail any actions and timelines to enable attendance and any interim provisions:

Below are some questions that might need to be considered when detailing the support to be provided for the student by the school. These questions serve as a guide only.

Area: Overall support

- Is it necessary to provide support during the school day?
- How can the recommended support be provided in the simplest manner, with minimal interruption to the education and care program?
- Who should provide the support?

⁷ Based on The Royal Children's Hospital Melbourne template

- How can the support be provided in a way that respects dignity, privacy, comfort, and safety?

Area: First aid

- Does the medical/health information highlight any individual first-aid requirements for the student, other than basic first aid?
- Does the school require relevant staff to undertake additional training modules not covered under basic first-aid training?

Area: Complex/invasive health care needs

- Does the student have a complex medical care need?

Area: Routine supervision on health-related safety

- Does the student require medication to be administered and/or stored at the school?
- Are there any facilities issues that need to be addressed?
- Does the student require assistance by a visiting nurse, physiotherapist, or other health worker?
- Who is responsible for management of health records at the school?
- Where relevant, what steps are in place to support continuity and relevance of curriculum for the student?

Area: Personal care

- Does the medical/health information highlight a predictable need for additional support with daily living tasks?

Other considerations

- Are there other considerations relevant for this health support plan?
- Has the student had surgery or has an ileostomy (a surgical opening) that now requires additional care?

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